Constructing Personal and Couple Narratives in Late Stage Cancer: A Narrative Analysis

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This thesis is dedicated to Lizzie Wyllie
1950 - 2009

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Contents

Abstract

An increasing number of people with terminal cancer are being cared for at home, often by their partner. This study explores the identity, experiences and relationships of people caring for their partner at the end of life and how they construct their experience through personal and couple narratives. It draws upon dialogical approaches to narrative analysis to focus on caring partners and the care relationship. Six participants were recruited for the study. Two methods of data collection are used: narrative interviews and journals. Following individual case analysis, two methods of cross-narrative analysis are used: an analysis of narrative themes and an identification of narrative types.

The key findings can be summarised as follows. First, in the period since their partner's terminal prognosis, participants sustained and reconstructed self and couple relationship narratives. These narratives aided the construction of meaning and coherence at a time of major biographical disruption: the anticipated loss of a partner. Second, the study highlights the complexity of spoken and unspoken narratives in terminal cancer and how these relate to individual and couple identities. Third, a typology of archetypal narratives based upon the data is identified. The *blow-by-blow* narratives illustrate how participants sought to construct coherence and meaning in the illness story, while *champion* and *resilience* narratives demonstrate how participants utilised positive self and relational narratives to manage a time of biographical disruption. The study highlights how this narrative approach can enhance understanding of the experiences and identities of people caring for a terminally ill partner.

Chapter 1

Introduction

The aim of this research study is to learn more about the experiences and couple relationships of people caring for a partner with terminal cancer. The research question is:

How do people caring for a partner with late-stage cancer construct their identity and experience through personal and couple narratives?

Choice of research topic

Much of my work as a systemic psychotherapist in adult mental health was with couples encountering adverse life events; this was frequently when one partner was experiencing mental or physical health problems. I have had an enduring interest in the interplay between biographical disruption (Bury, 1982) and couple relationships: my previous research focused on the impact of the collapse of a small business on couple relationships. I came to be interested in care relationships from a personal perspective. One year before starting this doctorate, my twin sister was diagnosed with terminal breast cancer and I cared for her for the last year of her life. This experience increased my awareness of the multiple dimensions of providing care and of family relationships in the context of a terminal illness.

Context of research

In the UK today, one in two people will have cancer over their lifespan (Cancer Research 2015); in 2012 one in four deaths in the UK were caused by cancer (Cancer Research 2014). Most people would prefer to die at home rather than in hospital or a hospice (Stajduhar and Cohen, 2009) although less than twenty per cent of the population in England and Wales do so (Gomes and Higginson, 2008). There is a growing acceptance that this is

often the best option. Monroe and Oliviere (2009) state that in the future there will not be enough professional carers to meet end-of-life care needs. The implications of these demographic factors and canonical discourses (prevailing social discourses) are that more people are providing end-of-life care for family members at home; much of this care being provided by partners. This being the case, I would argue that it behoves us to learn as much as possible about the impact of providing terminal care on individual identity and the couple relationship.

Previous studies

There is a vast body of work addressing the experiences of those providing family care in palliative care. Many of these are large scale studies focusing on the quality of life and health issues of care providers (Riley and Fenton, 2007; Harding et al, 2012). Other studies have focused on the care relationship (Hagedoorn et al, 2008). A number of studies (Perz et al 2011, Altschuler, 2012, Ussher et al, 2013) address the issue of gender in caring while Gunaratnam (2007) and Kellehear (2009) highlight cultural aspects. Systemic authors including Rolland (1994), Forbat (2005, 2009), Altschuler (2012, 2013, 2015) and Weingarten (2013) have made important contributions to our understanding of the couple relationship in terminal illness and are of particular relevance to this study.

From the beginning, the hospice movement has been informed by narrative ideas and they continue to play a vital role in our understanding of the experience of illness; Kleinman (1988), Frank (1995, 2010), Hydén (1997) Bury (2001) and Bingley et al (2008) have made significant contributions in this field. There are fewer narrative studies focusing on the experiences of people providing care although Mattingly and Lawlor (2000) emphasise the role of narrative studies in appreciating the family care provider's perspective. The larger quantitative studies provide invaluable data regarding the experiences, concerns and health of caring partners and family members, while the smaller qualitative studies provide additional insights into the detail of their lives, relationships and identity.

This study

In this narrative study I explore the identity, experiences and relationships of people caring for their partner at the end of life and how they construct their experience through personal and couple narratives. I am primarily drawing upon Riessman's (2008) Dialogic/Performance Analysis and Frank's (2010) Dialogical Narrative Analysis. Both have focused on personal illness narratives rather than the experience of caring partners or the care relationship and I have adapted their methodologies to suit this study. Six participants were recruited for the study through hospices and I have used two methods of data collection: narrative interviews and journals.

The layout of the thesis

In Chapter 2, I review the literature relevant to this study. Chapter 3 begins with a rationale for the study, to include the overall research objectives. I then describe the methodology, including my epistemological position and the theoretical underpinnings for the interviews, journals and narrative analysis. Ethical issues and self-reflexivity are discussed. Chapter 4 details the method used including recruitment, a description of the participants, the interviews, journals and data analysis. In Chapters 5 and 6, I present the findings of the study. Chapter 5 contains the individual narrative analyses: these are presented in some detail because I consider them to be a key element of the findings. Chapter 6 contains the cross-narrative analysis, including an analysis of narrative themes and a typology. Chapter 7 is the discussion chapter, in which I draw together the findings of the study, link them to a critical review of the literature and consider how the study intersects with and challenges existing literature. I consider the study's strengths and limitations and assess the quality of the study in relation to accepted guidelines. I revisit self-reflexivity and discuss the clinical implications of the study. This is followed by the conclusion.

Chapter 2

The literature review

Introduction

The purpose of this non-systematic review is to situate my study in the context of existing literature. The literature on family care providers and palliative care is vast and, while giving examples of a range of studies, I have focused more closely on those most relevant to this thesis, including narrative and systemic studies of the experiences of illness and the couple relationship. The review is presented under the following headings:

- Policy, family care providers and palliative care
- Culture and care
- Gender and care
- Studies on family care providers
- Systemic and other relational perspectives
- Loss and anticipatory loss
- Narrative in illness and palliative care

Literature search strategy

I searched databases (with no date restrictions) using a selection of search terms including:

couple / partner / spouse / relationship *plus*
illness / terminal illness /cancer *plus*
care / carer / caregiver *plus*
narrative / systemic / *plus*
identity /culture / gender.

Policy, family care providers and palliative care

In the UK, in 2012, 162,000 people died of cancer, one in four deaths (Cancer Research UK, 2014). One in two people in the UK is expected to have cancer at some point in their life (Cancer Research UK, 2015). Forbat et al (2009) note an increasing emphasis on self-management for people with long term health issues such as cancer in English health policy. Policy documents such as *Our Health, Our Care, Our Say* (Department of Health, 2006) represent a move towards promoting patients' involvement in decision making and management of their own care. The paper also emphasises the need for increased cooperation between NHS and Local Authority organisations, improving choice for service users and providing more individualised care. The World Health Organisation (2002) stated that palliative care should address the needs of families as well as patients.

Since the Carers' (Recognition and Services) Act 1995 there is a growing acknowledgement of the role of informal carers in the care of the long term and chronically ill. There are nearly seven million carers in the UK today (Carers' Trust, 2012), 58% of whom are women. Macmillan Cancer Support (2014) estimates there are over a million people caring for someone with cancer in the UK, nearly half of whom will suffer mental health problems. The National Carers' Strategy, (Department of Health, 2010) recognised the contribution made by informal carers in England and established guidelines to ensure they would be supported, remain healthy and not be financially disadvantaged. The Care Act (Department of Health, 2015) replaces most current law concerning adult carers and people being cared for. It outlines how local authorities should implement both carers' assessments and needs assessments, defines who is eligible for support; defines obligations on local authorities and how charges for residential care and community care should be implemented. The aim of the act is to clarify policy and improve service to those providing and receiving care.

A number of authors have made policy recommendations for the improvement of palliative care. Hudson and Payne (2009) maintain that support for family

carers is imperative both in ensuring the success of home care and in meeting the needs of carers physically, psychologically and financially. The authors warn that the rhetoric concerning good practice for meeting the needs of carers in palliative care is not always matched in reality. This point is emphasised by Forbat, Hubbard and Kearney (2009); organisations may espouse the principles of family support but fail to deliver in practice. This may in part be due to insufficient resources to either assess or address carers' needs. Forbat (2005) suggests a move towards a discursive framework, a relationship-based social policy, in which the perspectives of both the patient and carer are considered.

Arksey and Corden (2009) state that social care policies for carers in England tend to be generic and argue for more targeted policies for people who are terminally ill, taking account of the uncertainties of timing and progression of the last stage in life. Kellehear and O'Connor (2008) discuss the concept of *health-promoting palliative care*; translating hospice ideals of whole-person care to the public health context and promoting partnership between palliative care and the wider community. Monroe and Oliviere (2009) address the demographics of care and warn that in the future there will not be enough professional carers to meet end-of-life care needs. They emphasise the need to alter public attitudes towards care and to promote the capacities and resilience of families and communities to respond to the needs of the dying. There has been a recent increase in the public discourse around death and care of the terminally ill. Whereas in the past the topic would often be avoided it is now often the topic of discussion in all areas of the media; the BBC Reith lectures being a recent example (Gawande, 2014).

Most people would prefer to die at home rather than in hospital or a hospice although only eighteen per cent do (Gomes and Higginson, 2008). There is a growing acceptance that this is often the best option. In a review of factors influencing death at home in patients with terminal cancer, Gomes & Higginson (2006) emphasise the importance of assessment, public education and family support and empowerment. This is, however, also contingent upon partners or family members being willing and able to offer their time and effort

(Arksey and Corden, 2009). For many this will be the first experience of caring for someone who is dying (Hudson and Payne, 2009) but, in the context of a partner's wishes combined with current ideas of *a good death*, it could be hard to demur. Kellehear (2009) stresses the complexity of cultural issues concerning place of death and the need to be sensitive to individual and family wishes and avoid cultural stereotypes.

In this section I have sought to clarify the current policy context in which this study is located. This context informs society's expectations of family care providers such as the participants in this study.

Culture and care

The meaning of illness and informal caring is determined by the cultural context. In all cultures family, friends and neighbours support those who are old, sick and disabled in the community but it is only in the last thirty years that the concept of *the carer* has been recognised in the UK. Barnes (2006) argues that the identification of carers as a social group has been critical in terms of social policy, theory, practice and ethics but can also be problematic. The construction of caring and expectations of carers differ across different cultural groups and time frames.

Gunaratnam (1997) comments that in some languages there is no word for care; it is unnecessary when, as in some Asian cultures, caregiving is considered a normal part of family life. In some cultures the sense of filial duty is strong and it would be shameful to place an elderly parent in institutional care. Cardona, Chalmers and Neilson (2006), in a study comparing the role of the carer across different cultural groups within Australia, describe differing expectations between groups and note that some cultures may emphasise collective rather than individual life. Ka'opua, Gotay, Hannum and Bunghanoy (2005) consider the effects of culture and ethnicity on the adaptation of the partners of a group of Asian / Pacific Islander prostate cancer survivors in Hawaii. They claim that ethnicity acts as an integrating force when confronting

significant life events and provides a context for evaluating health and making meaning of the self in a changing experiential world.

In a Race Equality Foundation briefing paper, Gunaratnam (2007) addresses the issues which may be restricting ethnic minority access to palliative care; including misunderstanding or fears about palliative care, death and dying and being unable to speak the dominant language. Kellehear (2009) points out that while the western ideal of a *good death* may be to die at home cared for by the family, in some cultures this is not the case. He cites the example of Chinese and Japanese families who commonly view institutional care as the best option, and may view a death at home as unlucky. Gunaratnam (2007) also describes a potential conflict between western ideals of a *good death,* where the patient is aware of their diagnosis and able to make decisions about end-of-life care, and those of cultures where family members may take on decision making and even request the withholding of information from the patient.

Gunaratnam highlights the importance of balancing sensitivity towards end-of-life cultural practices against the possibility of oppressive power relations in families. She emphasises the need for training in cultural awareness and competence in this area. In a later study involving patients, carers and health and social care professionals, Gunaratnam (2008) critiques *cultural competence,* suggesting that the assumptions informing cultural competence models can be unhelpful for service users and professionals alike in not taking full account of the moral and ethical complexities of illness and care and in failing to take account of the *visceral and non-rational* elements of inter-cultural care.

Koffman and Higginson (2003) consider the meaning of pain and illness to be culturally determined. Relatives of deceased Black Caribbean patients were more likely to describe patients as having experienced high levels of cancer pain than their white British counterparts. Koffman, Morgan, Edmonds, Speck, and Higginson (2008) describe the meanings ascribed to pain by two ethnic groups. Both black Caribbean and white patients identified pain as a

challenge which needed to be mastered and as an enemy which represented an unfair attack. Black Caribbean patients also described pain as a test of faith and as a punishment associated with wrongdoing. These meanings influenced how patients were able to accommodate their distress. We can hypothesise that the meaning care providers give to pain and illness may be similarly culturally determined.

Altschuler (2013) highlights the importance of appreciating the potential difficulties and complexities faced by migrants who become ill. In the absence of an extended family network parents may turn to children for support with consequences for intergenerational boundaries. All migrations involve some loss and disruption and the losses experienced in illness can re-awaken emotions from migration.

The literature in this section underlines the importance of taking account of the cultural and ethnic context when considering the identity, experiences and needs of those providing family care and as such is critical to this study.

Gender and care

Gender inevitably lies at the heart of any discourse on illness, caring and relationships. Butler (1990) challenges normative ideas of masculinity and femininity by arguing that gender is perfomative. Rather than gender being understood as an internal essence, it is viewed as a sustained series of acts. In the context of a biographical disruption (Bury, 1982), such as a terminal illness, previously accepted gender roles may be challenged for both the ill person and their partner. In most cultures women still provide the majority of care in the family throughout the life-cycle, caring for children, the elderly and the sick. In heterosexual couples where the female partner is seriously ill, however, she will often be cared for by her partner. The studies cited below indicate the varied findings from the literature, reflecting the complexity of the issue of gender in the care relationship.

A number of authors have examined why women providing care appear to be more susceptible to distress than their male counterparts. Altschuler (2015) comments that it remains unclear whether women suffer more, are more likely to acknowledge distress or whether the burdens undertaken are greater. Perz, Ussher, Butow, and Wain (2011) concluded that women's gendered role is associated with unmet needs and burden of care, resulting in greater anxiety. Ussher, Sandoval, Perz, Wong and Butow (2013) found that women were more likely to report negative changes in the relationship with their partner, self neglect, social isolation, a worsening of physical health and anxiety.

Ussher and Perz (2010) found that both men and women self-silenced to prioritise their partner's needs and to avoid conflict. Women positioned self-silencing as a requisite of coping linked to constructions of idealised femininity whereas men positioned it as a normal aspect of masculinity. For both self-silencing is associated with depression and anxiety. Emslie, Browne, MacLeod, Rozmovits, Mitchell and Ziebland (2009) also reported men and women controlling emotions to protect partners and preserve household routines.

A number of authors have commented on how gendered expectations affect the experience of care. Hagedoorm, Sanderman, Buunk, and Wobbes (2002) put forward an explanation for gender differences in carer distress based on the concepts of role identity and identity-relevant stress. Women attribute feminine characteristics to themselves, such as sensitivity to others, and may have higher expectations of themselves in a carer’s role than do men. Thus, when they perceived themselves as not performing their caregiving tasks well, they experienced distress. Kellehear (2009) also noted the differing expectations put upon male and female carers and suggests that women may perceive or actually receive less support than is offered to men because men may be viewed as more vulnerable or less skilled in the domestic sphere generally. He suggests that men may make more demands upon a female carer than women do on a male carer. Ussher and Sandoval (2008) report similar findings. Women described being positioned as expert carers who were expected to be competent in a range of areas including decision-making,

physical caring and emotional support. This positioning led to over-responsibility, self-sacrifice, unexpressed and overwhelming emotions and an impact on physical health. Men, in contrast, positioned caring as a skill they had satisfaction in having mastered. The authors conclude that cancer caring is linked to gendered constructions and expectations which may impact upon coping and psychological health and should thus be a consideration for care providers.

Some studies have highlighted how traditional gender roles come into play in family care. Emslie et al (2009) found that some women organised cover for housework and childcare when they were ill, while some men made sure that their families were financially secure. Dale and Altschuler (1997) and Altschuler (2012, 2015) highlight how men and women may differ in how they react to caring for an ill partner. Women may express feelings more openly and seek help and support from others, while men may be more inclined to fear loss of power or losing control of their feelings. They may focus on problem-solving and withdraw from the family and friends. Altschuler comments that although women may experience higher levels of stress than men, the adjustment of both partners is better if the ill partner is a man. Men may find their partner's illness more difficult than the woman does herself. Women who take on additional responsibilities due to their partner's illness may gain more satisfaction from so doing than men who are forced to take on the more traditional female roles; this point is underlined by Ussher et al (2013) below.

Several authors have commented on positive aspects of caring for men and women. Emslie et al (2009) focused on gender and spousal support in couples with colorectal cancer. Both men and women valued their partner's role in providing emotional and practical support. Both reported mutual support and reciprocity. Ussher et al (2013) found that women reported personal strength and growth and positioned caring as a privilege. The men in the study reported increased closeness to the cared for partner. Forbat (2005) maintains that men may benefit from adopting the identity of a carer and that some men may characterise their caring role as above and beyond that of a

husband, thus eliciting a favourable assessment of their contribution from the recipient of their care. This concurs with the findings of Ussher and Sandoval (2008).

McGoldrick (2004) comments on the lack of discussion of gender in the literature on loss and highlights the differences in how society expects men and women to respond to death in the family. In western cultures women are usually expected to deal with the social and emotional tasks of terminal care and bereavement. The points McGoldrick raises are congruent with findings from the carer literature. McGoldrick reports that men and women differ in how they deal with loss, women being more likely to express grief, find comfort in rituals and accept support while men fear loss of control, focus on practicalities or seek refuge in work and may act out or abuse drugs and alcohol.

The literature reviewed in this section demonstrates the complexity of gendered constructions and highlights the differences in how men and women may experience and respond to caring for their partner. In this narrative study, gender and care are regarded as "performances" and I will examine how these concepts are enacted by participants in the context of the care relationship.

Studies of family care providers

Family care providers in illness

There have been a number of large scale studies analysing the quality of life of carers, including measures of physical and mental health, perceived burden and emotional distress; they are mostly based on a positivist epistemological position and use quantitative methodology. Cochran and Lewis (2005) conducted a critical analysis of intervention studies addressing partners' adjustment to breast cancer. Studies indicate that the partner's level of distress is usually at least as high as the patient's and that emotional distress

and depressed mood in the partner can have a negative impact on the patient, marital adjustment and the couple's ability to face new challenges. Couper, Bloch, Love, Macvean, Duchesne, and Kissane (2006) reviewed studies focusing on the psychosocial adjustment of the partners of men with prostate cancer. The literature suggests that partners suffer higher levels of distress than patients, yet believe the patient is more distressed. Some studies (Hagedoorn, Sanderman, Bolks, Tuinstra and Coyne, 2008; Kim, Kashy, Wellisch, Spillers, Kaw and Smith 2008) compared the level of distress in people with cancer and their partners and the reciprocal connection between them. Kim et al conclude that, although an individual's level of distress is the strongest predictor of quality of life, a partner's distress can play a significant role

Stenberg, Ruland and Miaskowski (2010) conducted a systematic review of the literature on the problems and burdens of family cancer carers. They found substantial evidence of the problems and increased responsibilities experienced by family carers and recommend clinicians include support for family members providing care as part of total or holistic care. The authors state further research is needed to better understand the caregiving experience over time and the influence of gender, age, cultural, ethnic and socioeconomic factors on caring.

Morris and Thomas (2001) ask; *How do carers negotiate their place in a cancer situation? How do they see their role in relation to the patient and the medical setting?* The authors suggest that when a carer's role is appreciated it is easier for them to attend to their own needs as well as those of the patient. Lethborg, Kissane and Burns (2003) found that significant others of breast cancer patients report having to adapt to the fear of losing their partner and the impact on their own mortality. They describe being unprepared for the role of caregiver. The authors conclude that partners should be considered an integral part of the care team. Forbat et al (2009) remind us that not only does cancer affect relationships, but relationships affect cancer, thus services supporting cancer patients should support the family.

Family care providers in palliative care

Informal care in the palliative care context is well researched. High levels of stress are recorded alongside emotional distress and inadequate support (Payne, Smith and Dean,1999). Fatigue, anxiety, depression and isolation are also reported (Riley and Fenton, 2007) and are seen to change with the disease trajectory.

Epiphaniou, Hamilton, Bridger, Robinson, Rob, Beynon, Higginson and Harding (2012) describe coping strategies employed by informal caregivers in palliative care. These include distraction activities; focus on the positive and protective buffering, which can be defined as hiding worries and concerns from a partner and avoiding disagreement in order to reduce stress and burden. Monroe and Oliviere (2009) emphasise the importance of the social, cultural, economic and environmental context. Kellehear (2009) concurs; he also highlights the additional difficulties caused by social isolation and financial hardship. Kellehear finds that differing views about care between the dying person and family care provider can cause distress.

Stajduhar and Cohen (2009) state that while some family members agree to provide end-of-life home care willingly, others may be doing so from a sense of duty or obligation. The carer's wish to provide home care is necessary for a good outcome. The authors identify the roles care providers may adopt including: physical care, symptom control, emotional support, advocate, social support and co-ordinator of care. These roles can be beneficial in providing a sense of satisfaction from fulfilling the wishes of the dying person and an opportunity to spend special time with them. They can help to find meaning in the situation and a sense of *giving back* to the dying person. Factors which facilitate a positive experience include: care decision negotiation between the care provider and patient, the care provider feeling their needs were considered and their views and contribution respected and feeling they had met the patient's needs.

A number of authors have made recommendations for improving the quality of palliative care. Monroe and Oliviere (2009) make the case for meetings with families receiving end-of-life care and give guidelines for interventions. Stajuhar and Cohen make recommendations for ensuring carers' needs are recognised and addressed and stress the importance of adequate round-the-clock healthcare support if required. Riley and Fenton (2007) and Milne and Quinn (2009) emphasise the importance of comprehensive assessment, given that care providers may be reluctant to ask for help. Milne and Quinn (2009) recommend targeted interventions including clear information and advice on accessing support.

Ashby and Mendelson (2009) address some of the ethical and legal issues affecting family carer providers in the palliative care situation, including defining the unit of care (patient or family) and capacity for decision-making. The authors recommend family meetings to resolve disagreements and, if this fails, taking legal advice. Ashby and Mendelson advise on strategies for dealing with requests for assistance to die and state that most people making such requests will accept optimal palliative care, with no attempt to prolong life, as an alternative. More recently this issue has been contested in the courts.

The studies on family care providers identify the impact on family members of providing care in terms of health, burden and quality of life and make recommendations for both practice and further research. The studies on care providers in palliative care highlight difficulties people may experience, coping strategies and positive aspects of care. Recommendations for the improvement of services for care providers are included. The systemic literature is reviewed in the following sections.

Systemic and other relational perspectives

Systemic perspectives on illness and cancer

In *Better Cancer Care,* Forbat et al (2009) make a compelling case for bringing a systemic framework to the understanding and treatment of cancer and the care relationship. They emphasise that, while cancer is a disease which resides in an individual, it affects multiple relationships. The authors point out that while there have been a large number of studies (such as those described in the previous section) focusing on the wellbeing of family care providers, they have not addressed the impact of the disease on the care relationship. The authors suggest that this should be the focus of professional support.

In the earlier family therapy literature Bowen (1976) and Paul (1965) describe how loss will impact on the whole family system, sometimes precipitating reactions or *shockwaves* not recognised by the family as connected to the loss. Rolland (1987) reminds us that family history of illness will inform how current illness is understood and responded to. Rolland (1989) highlights the importance of understanding the system created by the intertwining of three evolutionary threads: the illness, the individual and the family life-cycle. Rolland (1987) applies the concept of *centrifugal / centripetal* forces to families facing illness and notes that when illness occurs at a life-cycle stage when families are usually moving apart, such as children leaving home, it can be particularly disruptive. Rolland (1994) utilises a *Family Systems Illness Model* as a basis for understanding the impact of illness on the family, adults and children at all stages of the life-cycle and offers a comprehensive guide to interventions.

Rolland (1994) highlights the importance of considering the time phases of an illness in appreciating families' experiences. He identifies three broad illness phases; crisis, chronic and terminal. He suggests a time line which runs from pre-diagnosis through the initial adjustment period, the chronic phase, the pre-

terminal phase to death and the mourning period. Utilising a normative model, Rolland highlights the tasks and adaptations facing families at each stage and potential problems which may arise. He suggests therapeutic interventions to facilitate dealing with the challenges of the illness and reminds us that family members may not share current beliefs concerning the chronic or terminal nature of an illness. The progression of an illness is also critical in how it impacts on family relationships, whether progressive, constant or episodic. Drawing upon the work of Kluckhohn (1960), Rolland stresses the importance of noting a family's temporal orientation which may influence their experience of and reaction to an illness. A family more oriented toward the past may tend to draw upon multigenerational legacies and beliefs while a future oriented family may be more amenable to unfamiliar or innovative strategies or therapeutic options.

Forbat et al (2009) also highlight the importance of placing cancer in a temporal context. The authors underline the value of longitudinal studies in appreciating the iterative connections between experience of illness and life-cycle stages. The importance of understanding the meaning of illness over time and generations is emphasised. Hyden (1997) states that all forms of illness can rupture our sense of temporal continuity and that constructing illness as narratives can work to contextualise the illness within the overall biographical context.

Altschuler (2012) addresses the impact of illness and disability on family life and notes that, while there may be losses to contend with, in some instances illness can lead to improved relationships. She states that a life-threatening illness necessitates a radical change in how we see ourselves and relate to others and describes some of the tasks facing families dealing with this. These include: facing uncertainty and the threat of death, balancing acceptance and hope, reworking boundaries, balancing the demands of illness with other family needs and balancing the sharing of information with personal privacy. Altschuler raises the problem of holding onto an identity not consumed by the illness, also described by Frank (2010).

Several systemic writers introduce a narrative perspective to illness in the family. Byng-Hall (1995) combines systemic and attachment theories to explain how families must adapt their usual scripts to deal with serious illness and loss. Penn (2001) regards illness as a relationally traumatising experience for the whole family, who may show signs of physical stress in addition to feelings of isolation and helplessness. She describes how prevalent negative metaphors can combine with the inner voices of the ill person and create silence at a time when connection is most needed. Penn suggests narrative strategies to address this, using writing as a way of reintroducing communication in the family.

Some authors specifically address the issues facing families dealing with cancer. Robinson, Carroll and Watson (2005), who utilise the metaphor of *the family crucible of cancer* to describe families' experiences of living with cancer, highlight the ongoing struggle between feelings of isolation and connectedness. They describe how families try to make meaning of cancer in their lives and incorporate it into their world view. Like Kellehear (2009), Becvar (2005) draws our attention to the importance of social support for those coping with cancer. The author suggests society should develop more relational awareness, make peace with the inevitability of mortality and revise culturally constructed narratives around illness, particularly cancer. Acworth and Bruggen (1985) describe how family therapy can facilitate important family conversations even at the very end of life.

Forbat et al (2009) identify themes to highlight the meaning of cancer in people's lives. They examine the impact of cancer on relationships; the disease may affect a wide network of people, including family, friends and colleagues. The impact may be on physical and emotional health and there may be financial consequences. The authors highlight the limitation of studies which portray the patient / carer relationship as that of a giver and recipient of care and support rather than a reciprocal process, a point also made by Altschuler (2012). Forbat et al address the impact of relationships on the experience of cancer and how family dynamics affect the overall experience of illness. The importance of relationships with professionals for both patients

and family members is considered. The authors address how people relate to cancer itself and note how the identity of cancer has changed over the last twenty years, with advances in treatment and much improved survival rates. They discuss the societal impact of cancer; patients and partners may have to relinquish or change their employment with implications for identity and family finances.

In a recent systematic review of the literature on conceptualising distress in families in palliative care, Carolan, Smith and Forbat (2015) make the observation that there is no current consensus on the definition and parameters of distress in the palliative care literature. The authors propose a tiered model for conceptualising distress in families with progression from unitary to systemic constructs. The authors make the case for conceptualising distress as a systemic construct in future research; distress in one family member is related to another and distress in the family system is influenced by relational functioning.

Systemic perspectives on the couple relationship in serious illness

In an ongoing couple relationship, illness occurs in the context of the overall relationship, which may have lasted for many years. The couple bond has been compared to the mother-child bond in its intensity; although there may be cultural variation as to whether this is always the case. Gabb and Singh (2015) found that in non-Western family forms, the primary dyad is not always the couple but could be parent and child. The need to form an intimate bond with another seems to be universal (Jones, 1993). Jones suggests that, as the nuclear rather than extended family becomes the dominant western pattern, couples turn more to each other to meet emotional needs. This has implications for couples facing the serious illness and death of one partner. Rolland (1994) identifies the structural and emotional *skews* (imbalances) which may operate in couples dealing with chronic illness, including issues of power and control and intimacy. Altschuler (2012, 2015) highlights how issues of health status, power and dependency impact on couples when one is

caring for the other, perhaps informed by the value society places on being healthy.

Altschuler (2012) discusses the impact of illness on intimacy and reminds us that couples may need space to make sense of their own experience as an individual in addition to developing a shared understanding of what they need from each other. She points out that, although couples may turn to each other at times of difficulty, this can be hard because closeness may increase an awareness of what may be lost. Rolland (1994) notes that on receiving a diagnosis of serious illness couples may either draw away from each other or cling together. They may reassess their priorities and make the most of the time they have left together.

Weingarten (2013) examines *self and other loss* in the context of chronic illness, where each partner's experience flows into and affects the other. She describes how life is likely to become diminished for people who are chronically ill, with fewer resources available to negotiate a sense of self. The partner may face not only the diminishment and potential loss of their loved one but self-loss and the shrinking of their own world. Weingarten highlights how cultural and familial expectations of the loyal, devoted partner impact upon us and most will fail to meet the internalised ideal, potentially leading to a sense of failure. While some couples may find themselves more loving at such times, for others the strain of the situation may affect the qualities which made each partner lovable.

Altschuler (2015) discusses how a terminal prognosis creates a disjuncture between expected and lived experience for both the ill person and their partner, affecting beliefs about the predictability of the body and the couple relationship. The author suggests that while some couples may draw on beliefs and memories which reflect continuity between past, present and future, others find the change in body image and loss of the possibility of an autonomous life and imagined future impact on previous identity and the experience of intimacy for the couple. Altschuler highlights the tension between connection and individuality in couples and how this can complicate

communication when facing illness; protecting the partner sometimes reducing mutuality.

Skerrett (1998) describes a systemic study which examined the ways in which couples adapt to the experience of breast cancer. Couples were interviewed about their communication patterns, beliefs regarding illness and health, feelings of loss and disfigurement and problem-solving techniques. The meaning the couple made of the experience proved critical in lending coherence and direction to the couple's coping efforts, as was the couple's ability to define the experience as *our problem*.

Dyadic coping, protective buffering and communication in couples facing serious illness

A number of studies have focused on *dyadic coping* in couples facing cancer or serious illness. This concept identifies how couples may face adversity conjointly rather than individually, as *we* rather than *I*. Traa, De Vries, Bodenmann and Den Oudsten (2015) review the literature on dyadic coping and relationship functioning in couples coping with cancer and conclude that positive dyadic coping, open and constructive communication, support and joint problem solving were related to higher relationship functioning. Conversely, lack of support and negative dyadic coping may impede relationship functioning. Skerrett (1998, 2003) highlights the importance of dyadic coping *(we awareness)* in couples facing breast cancer.

Hubbard, Menzies, Reed and Forbat (2012) conducted a systematic review of the literature of the relational mechanisms and psychological outcomes in couples affected by breast cancer. They identified the relational components as couple coping, relationship functioning and satisfaction and communication. The study concluded that, although there was an association between relational and psychological variables, differences in theoretical frameworks and terminology made it difficult to identify which relational components had most potential to affect psychological well-being.

Manne, Badr, Zaider, Nelson and Kissane (2010) evaluated intimacy as a mechanism in couple communication after prostate cancer. The study indicated that the way in which couples talk about cancer-related concerns as well as the degree to which one or both partners avoids talking about them can either improve or reduce relationship intimacy, with implications for psychological distress. Goldsmith and Miller (2014) also draw attention to the complexity of how couples talk about cancer. The issues involved may encompass diagnosis and treatment options, who to tell about the cancer and how, self image, equity in the relationship and sexual intimacy. They also found that communication may vary over time and be perceived differently by each partner. Rolland (1994) highlights how shame, guilt and anger can impede communication between couples at times of illness. In contrast, Dale and Altschuler (1997) describe how couples can also experience a new closeness at this time.

A number of authors (Manne, Norton, Ostroff, Winkel, Fox and Grana, 2007; Langer, Rudd and Syrjala, 2007; Epiphaniou, et al, 2012; Traa et al, 2015) describe *protective buffering* in couples facing illness. This refers to couples avoiding discussion of sensitive topics to protect their partner (and sometimes themselves) from distress. It is viewed as likely to be detrimental to the couple relationship. Manne et al (2007) found that protective buffering resulted in more distress to couples reporting higher relationship satisfaction. Langer et al (2007) concluded that buffering was costly to relationship satisfaction in both the *bufferer* and the *buffered.* This was the case whether the *bufferer* was the patient or the partner. This issue related to the concept of *self-silencing* (Ussher and Perz, 2010) described above.

The sexual relationship in serious illness

A couple's sexual relationship is often affected by cancer or serious illness. Hawkins, Ussher, Gilbert, Perz, Sandoval and Sundquist (2009) found the majority of partners of men and women who had had been diagnosed and treated for cancer reported subsequent difficulties in the couple's sexual relationship. Some, however, also reported an increase in closeness and

intimacy. Couper et al (2006), in a review of studies of men with prostate cancer and their partners, found the patient's concern about their lack of sexual functioning was not usually shared by the partner. Ratner, Foran, Schwartz and Minkin (2010) state that the issue of sexuality following gynaecological cancer has not been adequately addressed and recommend psychotherapeutic intervention.

Altschuler (2012, 2015) discusses the complex relationships between self-image, desire, arousal and physical discomfort or limitations. Although for some couples illness can offer a respite from a difficult sexual relationship, for others increased emotional intensity can result in increased arousal. A satisfactory sexual relationship can provide comfort and intimacy and a reaffirmation of gender. Rolland (1994) outlines some of the sexual difficulties couples may encounter when one partner is ill but states that couples who redefine intimacy in broader terms than purely sexual can adapt more successfully to losses in the sexual relationship.

There have been relatively few studies focusing on sexuality and intimacy in terminal illness. Taylor (2014) suggests that in a couple facing terminal illness, the couple relationship is also dying. She describes how couples may go through stages of connecting, disconnecting and then reconnecting as they cope with illness. Disconnecting can be precipitated by medical treatments, disfigurement and the use of equipment, such as masks. The participants in the study understood sexuality and intimacy to be relational experiences. Connecting in the couple relationship was experienced as a sense of belonging and a renewal of affectionate bonds and included but was not dependant upon intercourse or sexual satisfaction. Taylor recommends that clinicians make openings for discussion of these issues.

Couple interventions

Couple interventions in serious and terminal illness are important to consider in this review in terms of any clinical applications of the study. Interventions can take many forms, including systemic therapy (e.g. Altschuler, 1997, 2012,

2015; Rolland, 1994, 2004), emotionally focused therapy (EFT), which facilitates the expression of emotion, (e.g. McLean, Walton, Rodin, Esplen and Jones 2013), family focused grief therapy (Kissane and Bloch, 2002; Kissane, McKenzie, Bloch, Moskowitz, McKenzie and O'Neill (2006) and psycho-education and support (e.g. Northouse, Mood, Schafenacker, Montie, Sandler, Forman and Kershaw, 2007). The interventions described range from single case studies through to large randomised controlled trials (RCTs). Many studies highlight the importance of open communication in couples facing serious illness.

Drawing upon both diadic coping and narrative, Skerrett (2003) (discussed above) devised an intervention, drawing on the work of Frank (1995), for people with breast cancer and their partners. Couples were helped to build an awareness of each other's narratives of the illness, build more relational stories and thus reduce the isolation of the illness experience. Hopkinson, Brown, Okamoto and Addington-Hall (2012) conducted a systematic and narrative review of 23 cancer couple interventions. A pattern emerged of improvement in the emotional health of cancer patients and their carers when the intervention included support for the patient-family carer relationship. The authors concluded that further investigation is warranted. McLean, et al (2013) conducted an RCT of 42 cancer patients and their carers which demonstrated the effectiveness of EFT couple interventions for patients facing advanced cancer. Burwell, Bracker and Shields (2006) describe an attachment based intervention, also using EFT, for insecurely attached cancer patients and their partners. There have been several RCTs of interventions with men with prostate cancer and their partners. Northouse et al (2007) conducted a study with 263 couples and found those receiving the couple intervention, offering information and support, reported improved quality of life, better communication and less negative appraisal of life, hopelessness, uncertainty and symptom distress.

Some studies highlight the lack of research in this area. Chambers, Pinnock, Lepore, Hughes and O'Connell (2011) conducted a systematic review of RCTs of psychosocial interventions for men with prostate cancer and their

partners. They concluded there were limitations in the research on effective ways to improve adjustment for these couples and little research targeting minority groups and the concerns of men with advanced disease.

A number of authors have made recommendations for future studies and treatment of couples in serious illness. Rolland (1994) utilises his *Family Systems-Illness Model* to provide a basis for interventions to address problems based on intimacy, sexuality, gender and co-parenting. He recommends addressing *relationship skew* introduced by the illness by facing illness as a couple, establishing healthy boundaries, balancing the roles of patient and carer and addressing gender issues. Rolland suggests a flexible approach as to whether to see couples together or individually. Altschuler (1997) identifies some of the issues to consider when working with couples in illness, including the couple's understanding of the illness and its causes, how to live with threatened loss, connections between past, present and future priorities and expectations, mutuality in the patient / carer relationship, physical intimacy and hopes and expectations for the future. She recommends addressing similarity and difference in the couple, losses and gains and the impact of physical caring.

Some authors have considered couple communication in illness. Rolland (1994) and Dale and Altschuler (1999) stress the importance of open communication between couples facing serious illness. Rolland outlines what he considers important discussions at this time including: the illness and its psychosocial demands, beliefs about the illness, how to live with potential loss, personal and relationship priorities and, in a terminal illness, end-of-life decisions. Rolland cautions that couples may not be ready to address sensitive issues at the same time and not everything has to be discussed.

The benefits of a systemic perspective in considering the multiple aspects of family carers in illness and cancer contexts are highlighted. The systemic studies reviewed demonstrate the range of issues couples may face when encountering serious illness. Some studies indicate illness can engender increased closeness in couples. Communication patterns in couples facing

illness are considered. Dyadic coping and open, constructive communication patterns are described as beneficial whereas protective buffering can be detrimental to relationship satisfaction. Studies focusing on the impact of illness on sexual relationships are considered. Family therapy informed interventions which have been used with couples facing serious illness are reviewed. Many of these have demonstrated positive outcomes; other studies highlight the need for further research in this area. All of the studies reviewed in this section are relevant to this study in highlighting difficulties and positive aspects couples may experience when facing illness. The following section considers frameworks for loss.

Loss and anticipatory loss

As this study is concerned with the loss of a partner, I have highlighted some of the theoretical frameworks for the processes of anticipatory loss and mourning. Walsh and McGoldrick (2004: pp8) comment that;

> *"…a systemic perspective on loss remains sorely lacking in most research, clinical theory, training and practice".*

In a family or couple living with terminal cancer, the grieving may begin long before the actual bereavement; Rolland (2004) discusses anticipatory loss in terminal illness. He views it within a developmental framework, the meaning of loss being informed by the particular life-cycle stage, the family's previous experience of loss and the course of the illness. Rolland describes possible emotional responses to anticipatory loss, including: separation anxiety, existential aloneness, denial, sadness, disappointment, anger, resentment, guilt, exhaustion and desperation. There may be fluctuation between negative experiences and positive periods of heightened intimacy and appreciation of life together. Families may experience ambivalence towards the ill person, sometimes wishing to protect and care for them, sometimes wanting to escape the situation. They may rehearse the process of loss and the imagined scenes of suffering. The patient may dread becoming a burden to the family

while the caregiver may experience guilt at their own dread of future responsibilities.

In the past, authors and clinicians have utilised stage or phase theories of grieving to increase awareness of the processes of dying and mourning. Kubler-Ross (1970) identified five progressive stages of grief: denial and isolation, anger, bargaining, depression and acceptance. Parkes (1972) described a succession of phases of grieving including numbness, followed by yearning, which may include anger and irritability, then disorganisation and despair, followed finally by recovery and reorganisation. More recently authors, including Rolland (2004), Fredman (2003) and Altschuler (2012), have critiqued these concepts insofar as they suggest there is a correct procedure for mourning. Altschuler states that our responses are much more varied than this; different people find different ways of managing loss. Rolland agrees that there can be many effective coping strategies for mourning. Fredman warns of the dangers for clinicians in using a model in a prescriptive way rather than listening closely to the family member's experience.

McGoldrick et al (2004) highlight the cultural variations on mourning. Values and practices may vary enormously and clinicians should be careful about definitions of normality in responses to loss. Culture may impact upon time-scales, intensity and how grief is expressed. The authors suggest taking time to understand a family's values and beliefs concerning all aspects of death when planning interventions. Byng-Hall (2004) identifies steps in the process of facing up to loss and examines the role of family therapy in rewriting scripts of mourning. Imber-Black (2004) explores how normative family rituals can facilitate mourning and rituals can also be designed to address specific issues.

The theoretical frameworks for loss and anticipatory loss are important to consider in a study focusing on the experience of caring for a partner with a terminal illness. It is likely that participants in this study will already have started the mourning process. The following section reviews the place of narrative in illness and palliative care.

Narrative in illness and palliative care

Narrative and illness

Bingley et al (2008) describe the increase in narrative accounts of illness from the perspective of professionals, patients and family care providers over the last thirty years. These accounts can be found not only in the academic literature but in books, magazines, television, radio and, increasingly, the internet. Kleinman (1988), an anthropologist and psychiatrist, was one of the first authors to highlight the importance of narrative in understanding the subjective experience and meaning of chronic illness. He recognised the importance of cultural and relationship contexts in determining our experience of illness and others' response to it. Kleinman not only interrogates the meanings of symptoms and disorders per se but also their meaning within a particular life and history. He describes narrative as the way people shape and give voice to their suffering. Mishler (1984) describes illness narratives as an attempt to redress the balance against the dominant voice of medicine.

Hydén (1997) reviewed illness narratives in the preceding decade. He considers what can be accomplished with illness narratives, the social context of telling and its influence on the narrative, narrative typologies and problems with organising narratives. He maintains that illness narratives can be used to study not only biomedical reality, but also the illness experience and its social and cultural underpinnings. Hydén defines the function of illness narratives: to construct an illness experience, to reconstruct a life history, to make illness understandable and finally to collectivise the illness experience. Hydén and Brockneier (2008) state that illness narratives allow the sufferer to cope with the intrusion of illness by situating it within the context of ongoing biographical narratives. They maintain that narrating suffering is not only representing it but also expressing and performing it and making it part of the lives of others.

Other authors have also explored the function of narrative in times of illness. Frank (1995) describes serious illness as *a call for stories.* Stories can repair

the damage done by illness to one's sense of self and purpose and they are also required to inform others of what is happening to the ill person. Frank (1994) further elucidates the function of illness narratives: to gain a public voice for a private experience, to sustain one's voice against the voice of medicine and to situate illness experiences in the context of a whole life. Riessman (2008) stresses the meaning-making function of narrative at times of biographical disruption such a serious illness. Bury (2000) concludes that language and personal narratives are important in maintaining a sense of identity at times of adversity by helping to restore meaning.

Several authors have categorised illness narratives into typologies, or groupings of narrative types. Frank's (1995) typology includes: *restitution, chaos,* and *quest* narratives. Frank's typology is explored in more depth in the methodology chapter. Robinson (1990) also identified three different narrative types, based upon the illness trajectory: *stable, progressive* and *regressive.* Hydén (1997) critiques typologies such as these as being based upon a limited range of narrative genres. He suggests an alternative typology based upon the relationship between narrator, narrative and illness. Hydén proposes three narrative types: *illness as narrative*, in which the narrator, illness and narrative are combined in one person, *narrative about illness*, such as those provided by clinicians, and *narrative as illness*, in which the illness is generated by the narrative. Bury (2000) also describes three narrative types. The *contingent* narrative is concerned with beliefs about the origins of the disease or illness episode and its effect on everyday life. *Moral* narratives explore changes in the relationship between the individual, their illness and their social identity, while *core* narratives address connections between the experience of illness and deeper cultural understandings of suffering and illness.

Some writers have addressed the limits and dangers of narrative in this field. Gunaratnam (2009) reviews narrative in terms of its *creditworthiness* and practical applications. Riessman (2008), Bingley et al (2008) and Andrews, Squire and Tamboukou (2008) also consider the validity and trustworthiness

of narrative. Riessman concludes that narrative studies should be assessed within the context which framed them.

Narrative and palliative care

The modern hospice movement in the UK started in the 1950s and 1960s. Gunaratnam (2009) describes how narrative has been important to the hospice movement since its inception. Cicely Saunders, working with people who were dying in London, recorded over one thousand patient accounts on which she based the principles of palliative care. She emphasised the importance of making time to listen closely to patients' stories (Clarke, Small, Wright, Winslow and Hughes (2005). Based on these narratives, Saunders developed the concept of *total pain*, which encompassed the physical, psychological, social, emotional and spiritual aspects of pain: palliative care was designed to address them all. This holistic model involved a number of interventions including personalised pain relief, rehabilitation, physiotherapy, counselling for both patients and families and advice on benefits.

Saunders (1988) recognised that her work in the 1960s was influenced by the current developments in medical practice including new drugs, new methods of accessing information on patients' needs, pain clinics and psychotherapeutic approaches for loss and bereavement. The *narrative turn*, described by Riessman (2008), which challenged realist traditions of knowledge, also informed critiques of medical dominance in health care. From the 1980s onwards, there has been a steady growth in the interest and use of narrative methods in palliative care. Key figures in this movement have been Bury (1982, 2001), Kleinman (1988), Mishler (1986, 2002) and Barnard, Towers, Boston and Lambrinidou (2000). Barnard et al used a combination of participant observation, interviews and journals in a narrative study of life experiences, including the perspectives of patients, families and staff. Bury (2001) attributes the increase in palliative care narratives to changes in morbidity patterns, more available information about illness and disease and public debates regarding the effectiveness of medicine.

In recent years a number of authors have reiterated the importance of narrative in this field. Gunaratnam (2009) highlights the continuing value of narrative in appreciating the experiences of patients, carers and professionals. Bingley, Thomas, Brown, Reeve and Payne (2008), following Saunders, note the importance of attending closely to both patients' and carers' stories, not only to improve our understanding of an individual's needs, but also in the development of policy and practices effective in supporting people at the end of life. These points are emphasised by Cotterell, Findlay and Macfarlane (2009). McDermott, Bingley, Thomas, Payne, Seymour and Clark (2006) focused on viewing patients' needs through professionals' narratives while Romanof & Thompson (2006) combined narrative, ritual and expressive arts in a study to explore the construction of meaning in palliative care.

Narrative and family care providers

A number of authors recognise the value of narrative in increasing our knowledge about the lives and concerns of family care providers. Mattingly and Lawlor (2000) emphasise the role of narrative studies in appreciating the complexity of their perspective. Mcilfatrick, Sullivan and McKenna (2006) suggest that couples have often faced the illness journey together: illness narratives in the voice of the caring partner may in some aspects mirror those of the ill person. In the varied examples of care providers' narratives from the academic literature given below, the common factor is how narrative studies allow for in-depth examination of the experience, relationships and identity of people caring for a partner. I include some studies which combine the perspective of both partners and finally cite three examples of caring partners' narratives from the non-academic literature.

Eriksson and Svedlund (2006) conducted a narrative study with middle-aged women caring for a chronically ill partner. The illness is characterised as the *intruder* in the relationship. The women described detachment from their partners' lives, changes in relationships and loneliness. They expressed a wish to be loved as a wife rather than a care provider. Mcilfatrick et al (2006) compared the experience of caring partners in a chemotherapy day centre

and in-patient unit and found both groups' experiences followed their ill partner's in terms of transitions of the illness. The study identified roles adopted by caring partners in the day hospital, including: *companion*, *protector, practical caregiver* and *advocate.*

Carter (2001) in a narrative study of female cancer carers, explored the issues around uncertainty for this group and concluded that information provided by practitioners was often more harmful than helpful and made recommendations for improvement. A Finnish study, (Lindholm et al 2007), examined the narratives of the partners of women with breast cancer. These partners described having no role in the nursing care of their partner and expressed a desire for inclusion, communication and information. The authors conclude that partners could be a source of strength for women with breast cancer.

In contrast to some of the more negative aspects of caring described above, Wong et al (2009), in a study using analysis of narrative themes, highlight positive and beneficial aspects identified by carers. These include personal growth, strength, acceptance, deepening of the relationship with those cared for and altered perspectives on life. Hudson and Payne (2009) note the potential positive aspects of caring for a terminally ill partner and warn against pathologising or over emphasising ill effects.

Other studies have drawn upon the narratives of both patients and their partners. Little et al (1999) explored the meaning of approval and disapproval for colorectal cancer patients and their partners in the medical context, both in terms of perceived judgement on themselves and how they viewed others. In a further study of both cancer patients and their partners, Little et al (2000) explored the issue of vulnerability, defined as susceptibility to harm. They emphasise the importance of *reading for vulnerability* in both groups and taking account of it in health care transactions.

In a palliative care context, Murray et al (2003) used narrative analysis to compare the experiences of lung cancer patients and their caring partners in Scotland and Kenya and found differences not only in resources available for

patients dying from cancer but also in their lived experience of illness. Clayton et al (2005) used narratives as part of a study to explore how to talk about the end of life with cancer patients and those caring for them. The paper highlights strategies and language which could be useful in these discussions. Cotterall et al (2009) emphasise the importance of service user involvement in palliative care policy and demonstrates how carers' as well as patients' narratives can inform, challenge and improve palliative care.

In addition to the growth in illness narratives in the academic literature, a number of writers have written memoirs of experiences of caring at the end of life. Dansie (2012) wrote a chronological account of caring for a close friend as she was dying of cancer, complicated by lupus. She charts the gradual deterioration in all aspects of her friend's condition and reflects on her own reactions and the relationship with her friend as she provides physical care. Bennett, a Pulitzer prize-winning author (2112), writes an account of an illness journey in which she transforms from wife to caregiver and advocate. Coutts (2014), in *The Iceberg*, a companion book to her journalist husband's illness memoir, writes an account of her husband's illness and death from a brain tumour as she cares for both for him and their young child. These extended, detailed and very personal accounts provide a unique insight into how people construct their lives, experiences and relationships as they care for a dying partner. Narratives such as these, particularly when they are widely reviewed in the media, have an important function of raising public awareness of the role of cancer care providers in the community.

Illness narratives are a rich and varied resource for understanding the experience and meaning of illness for the individual. Typologies of illness narratives are reviewed. The role narrative studies continue to play in the palliative care literature is emphasised. The authors reviewed conclude that narrative has a valuable role in research. The care providers' narratives reviewed include both academic studies and personal stories. Both provide perspectives on the lives and relationships of family care providers. The narrative literature reviewed has been important in considering how ill people and those who care for them construct their experience. Reviewing this

literature has highlighted the potential for further narrative studies on people providing care for a partner at the end of life.

Summary of the literature review

Previous studies of family care providers and care relationships have been critical in our understanding of the health, quality of life and challenges facing people caring for a terminally ill partner and have made an important contribution to social policy. In this review I have sought to situate this study within the relevant literature. I have included English policy relating to family carers and palliative care and have given an overview of the literature on the experiences and quality of life of care providers, with particular reference to culture and gender. Systemic studies on illness and caring have been reviewed, with a particular focus on the meaning of illness in couple relationships. As this is a narrative study, I have reviewed the narrative literature relating to palliative care, illness and family care. Illness narratives have played a vital role in our appreciation of the subjective illness experience and its social and cultural underpinnings (Hydén, 1997).

The literature review suggests there are relatively few narrative studies focusing on the experience, identity and relationships of people caring for a terminally ill partner. There is a comprehensive literature relating to the health and quality of life of family care providers in palliative care and a number of studies focusing on the care relationship. There is a growing literature of personal illness narratives and these narratives have made an important contribution to our understanding of the experience and meaning of illness. In applying dialogical narrative analysis, as described by Riessman (2008) and Frank (2010), to the narratives of people caring for a terminally ill partner, this study offers an original contribution to the literature.

*

In this chapter I have reviewed the literature relevant to this study. The following chapter gives the rationale for the study and details the methodology, including epistemology and the main theoretical influences informing the research.

Chapter 3

Methodology

Introduction

This is a small scale, narrative study focusing on the experiences, identities and relationships of people currently caring for a partner with terminal cancer at home. In this chapter I give the rationale for the study and the overall research objectives. I detail the theoretical framework underpinning the study and identified key influences informing how the study was designed and conducted. I address ethical issues, self-reflexivity and relational reflexivity.

The rationale for the study

In this study I aim to build on some of the work described in the literature review. In 2012, one in four deaths in the UK was due to cancer (Cancer Research 2014). Many people prefer to die at home and, of the 18% who do (Gomes and Higginson, 2008); many will be cared for by their partner. The literature review indicates that, despite the large literature on family care providers and the care relationship and the large number of narrative studies focusing on illness in the individual, there are few narrative studies focusing on couples facing a terminal illness from the perspective of the caring partner. This is the area I address through the following research question:

How do people caring for a partner with late-stage cancer construct their identity and experience through personal and couple narratives?

In applying dialogical narrative analysis previously applied to illness narratives to the experience and relationships of caring partners, I aim to introduce a different perspective from previous studies. I am particularly interested in the meaning-making function of the narrative, what identities are being performed, what previous narratives are being drawn upon and how the context informs

the narrative. In this study I aim to achieve a detailed and nuanced investigation into the identities, experiences and couple relationships of people caring for a partner at the end of life.

Systemic authors have made important contributions in conceptualising couple, family and organisational issues in illness and terminal care. They have demonstrated the value of systemic interventions for some couples at the end of life. This study is underpinned by a systemic theoretical framework and aims to draw out and contribute implications for the systemic field.

Overall research objectives

The purpose of this study is to examine the experiences and relationships of people caring for a partner who is dying of cancer at home. This is a narrative study using both interviews and journals to learn more about the lives, reflections, identities and relationships of partners of the terminally ill. I use narrative analysis to examine how individual and couple narratives are being used to construct the experience and couple relationships of people caring for a partner at the end of life.

Epistemological position

This study aims to produce knowledge of the texture and detail of the lived experience, identities and relationships of the participants. Qualitative methodologies span epistemological positions from naïve realist through to radical constructionist (Willig, 2001, Madill, Jordan and Shirley, 2000). I position myself as a contextual constructionist (Willig and Billin, 2012). I recognise my part in the knowledge production; I determined the interview context, the participants were responding to my questions which in turn were informed by my beliefs and current social discourses. The context of the interview as part of a research study, the participants' relationship to the referring agency and their relationship with me all impacted on the nature of

the talk. Rather than viewing knowledge as an objective truth waiting to be discovered, I view the knowledge produced in the interviews as co-constructed; meanings were generated through talk. Knowledge is viewed as historically and culturally located and so not necessarily transferable to other contexts. Although the journals were not produced in dialogue, they were nevertheless informed by the preceding interview, the request to write a journal and by the knowledge that they would be read by others. The analysis of the interviews and journals is my interpretation and as such is another layer of co-construction.

My approach to this study has been informed by the work of Riessman (2008) and Frank (2010) who have focused on biographical disruptions precipitated by illness. Both authors cite Goffman (1969, 1974), Bakhtin (1981) and Mishler (1986, 1995) as important influences in their work. Frank rejects a *mimetic* understanding of stories, they do not represent an external reality but are themselves a creative interpretation that is worthy of attention. Mishler (1986) argues that the self is continually constructed through narrative; identities are discursively constituted, rather than a stable self being reflected in language. These concepts inform my epistemological position. Bakhtin (1981) states that form and meaning emerge between people in a particular social and historical context. All words are saturated with meaning from previous usage and analysis is never neutral.

The interviews were regarded as a *snapshot*, they reflect one moment in time in a particular context. A different occasion with a different interviewer would have produced a different narrative. Alongside my epistemological stance as a contextual constructionist, I recognise the difficulties being faced by some of my participants as they care for their dying partners and I acknowledge my wish to give voice to this group.

Choice of Methodology

I tried to choose a methodology which would be congruent with my epistemology and would best represent the identities, experiences and relationships of the participants. I initially considered using grounded theory for the analysis of the interviews. Although some earlier models of grounded theory had a more realist orientation, many studies now adopt a social constructionist perspective (Charmaz, 2006). For a researcher, grounded theory has the advantage of offering recognised procedures for approaching data analysis. This method has been used extensively for the study of social processes, particularly in the study of illness. The research question in this study, however, was not focused on exploring processes. Another possible choice for this study could have been Interpretive Phenomenological Analysis. This methodology has the benefit of capturing experience and unpacking the meaning and offers clear and systematic guidelines (Willig, 2001). Neither grounded theory nor I.P.A. method offer the same opportunities for a focus on the performance of identity and couple relationships as narrative analysis.

There are many forms of narrative analysis and the methodology I chose, Dialogical Narrative Analysis as described by Frank (2010) and Riessman (2008), appeared to be most appropriate for this study because of the focus on context. Possible disadvantages of this methodology include the following. There is less clarity regarding how to proceed with the analysis than with some other methodologies and this increases the possibility of becoming overwhelmed by the data. The analysis relies heavily on the selection of data and interpretation of the individual researcher. It is possible to remain at the level of description rather than undertaking a more rigorous analysis. Squire et al (2014) highlight the challenges of balancing the amount of data presented with the interpretation when communicating narrative research to others. They warn against the assumption that narrative provides fundamental insights into social existence and stress the importance of looking beyond narrative. The authors remind us that the ubiquity of narrative can also be problematic; narrative has been criticised for being simplistic. There are relatively few guidelines regarding how to proceed with cross-case analysis in dialogical

narrative analysis. One method, constructing a typology as described by Frank (2010), runs the risk of limiting narratives to previously identified types. I believe with care and supervision these potential difficulties of narrative analysis can be addressed.

Rationale for design

The chosen methodology fits with my epistemological position. In order to best address the research questions I decided to focus in detail on individual narratives of people caring for a partner with late stage cancer, defined in this study as people who are expected to die within six months. A qualitative study, using a narrative approach, provided the space and flexibility to elicit and analyse participants' experiences, identities and relationships in much greater depth than would be possible using a quantitative methodology. All aspects of the study are informed by a narrative perspective.

I use two methods of data-gathering to maximise the opportunities to explore the lived experience of people caring for a partner at the end of life. The interviews were co-constructed narratives mainly focused on areas relevant to the research question while the journals allowed the freedom for participants to reflect upon their current life and relationships in a more individual way, allowing the emergence of the written self and accessing both spontaneous thoughts and more considered reflections.

The interview

Some methodological considerations

The research interview is the most commonly used method of data collection in qualitative research studies and, combined with the ubiquity of interviews in the media, has the advantage of being familiar to research participants (King and Horrocks, 2010). There are many different types of qualitative interviews ranging from biographical interviews elicited from one opening question

(BNIM: Rosenthal, 1993) through to interviews closely based upon a structured guide.

Potter & Hepburn (2005) reviewed the role of qualitative interviews in psychology research and highlighted common problems. The first group of problems are defined as *contingent* and include failure to take account of the interactional nature of interviews and the subjectivity of the researcher, not representing all aspects of the interview in transcription, a lack of specificity in analysis and insufficient attention paid to the method of recruitment or sampling. These problems are considered avoidable in a well designed study. I addressed these issues in the following ways. Coming from a social constructionist perspective, the position and contribution of the researcher were acknowledged. My speech was recorded, transcribed and analysed as part of the data. I attempted to base my analysis closely on the data to address issues of specificity. The effect of providing prior information about the study to participants was considered in both the interviews and the analysis.

The other set of problems are defined by Potter and Hepburn as *necessary* and more difficult to avoid. The first is concerns flooding the research with social science agendas and categories, so fitting the data into predetermined frames. The second, based on the work of Goffman (1981) is concerned with a lack of clarity between current and reported speech in interviews, for example whether an interviewee is speaking for themselves or as a representative of a category. There may also be a lack of clarity as to who is the audience, the interviewer or the wider world. I have considered this issue in my analysis. The third problem addresses the interviewer's and interviewee's stake or interest in the research. Interviewers who are also the researcher, may clearly have a stake in the outcome of the research. I have addressed this issue in the *Self-reflexivity* section of this chapter. The interviewee may also have a particular agenda in participating in the research. The final difficulty raised by the authors concerns the effect of using *psychological language* in interviews. I tried to ensure my use of language in interviews was clear and free of jargon. I acknowledge the importance of

these issues and have given them consideration in the way the interviews and analysis were conducted

The narrative interview

Interviews provided the opportunity to focus in depth on the research question and the freedom to explore it in ways most meaningful to the participants. (Chase, 1995); Mishler (1991) and Hollway and Jefferson (2008) have critiqued survey interviews in that the question/answer format can repress or close down the telling of a story. In contrast, narrative interviews allow for the participants story to be told in a way which makes sense to them. Hollway and Jefferson, following the biographical-narrative-interpretative method (BNIM) of narrative interviewing developed by Rosenthal (1993), describes four principles of a narrative interview. Interviewers should use open-ended questions, elicit stories, avoid *why* questions and follow-up using the respondents own ordering and phrasing. In my interviews I have generally followed these guidelines. The BNIM (Rosenthal, 1993) focuses on biography and usually begins with a single request, such as, *"Please tell me your life story."* Hollway and Jefferson (2008) adapted the method to suit the context of their research (fear of crime) and used the same principles but in more focused interviews, which they believe were particularly appropriate with the *defended* interviewees in the study.

Jovchelovitch and Bauer (2000) acknowledge that interviewees will inevitably be influenced by what they believe an interviewer knows about a topic and what they believe the interviewer expects to hear. They describe an interview technique with minimal talk from the interviewer. After presenting the research topic, the interviewer offers no verbal input during the main narration and minimal questioning thereafter. The authors' focus is on the story rather than the teller.

Riessman (2008), following Mishler (1986), describes interviews as *narrative occasions.* She identified the change from interviewees being seen as a passive participant being questioned by an active, facilitating interviewer to

conversations in which the interviewer and participant actively co-construct narrative and meaning. A narrative interview allows for a sustained account by the participant. Riessman observes that generating narrative requires longer turns at talk than is usual in other conversations but the usual rules of conversation apply. These include turn-taking, relevance and entrance / exit talk. Participants are encouraged to tell their story in their own way rather than narrowly responding to the agenda and questions of the interviewer and one story may lead into another. The interviewer can usefully encourage reflection on association and meaning across stories. Riessman recommends eliciting specific examples and detail rather than generalities. She comments that narrative interviews involve researchers relinquishing some control of the interview and this changes the power balance. She notes that while the wording of questions is important, emotional attentiveness and reciprocity are also critical. Riessman comments that narrative interviewing is hard work and takes time; it requires the interviewer to put aside the self in order to enter the world of another.

In this study the narrative interview as described by Riessman was appropriate. The method has similarities with my previous interviewing experience: following feedback and exploration of meaning. Allowing the participant to tell their own story appealed to me. The BNIM was useful to consider as a technique but this was not a biographical study. The length of the BNIM and focus outside the participants' current concerns would have been less appropriate to people caring for a dying partner. Jovchelovitch's and Bauer's (2000) technique would be less useful for this study because I am focusing on the identity of the interviewee in addition to the topic.

I was aware of the sensitivity of the interviews and tried to ensure that it was not an overall negative experience for the participants. My experience as a systemic psychotherapist informed the pattern of the interviews. Burck (2005) highlighted the advantages of experience as a systemic therapist in research interviews including self-reflexivity, the ability to follow feedback and unpack meanings and the ability to elicit and hold multiple perspectives. Following Tomm (1988) and Burck (2005) I regarded the interviews as *interventive,*

potentially introducing new connections and perspectives for the participant. I consciously underlined some of the constructive reflections introduced by interviewees and sought to leave participants in a positive state of mind.

The interview guide

The interview was based on a guide (see appendix IV) designed to address the research questions. The guide was informed by my previous experience of working with couples dealing with a serious illness, my own experience of caring for someone who was dying, conversations with acquaintances who had cared for a terminally ill partner and by the relevant literature. The interview covered the couple's history and relationships and the impact of the terminal illness upon them. The guide was useful in helping to crystallise the focus of the study and was potentially an aide memoir when conducting the interviews. It helped to explain the nature of the study to the various panels from which ethical approval was required. In practice, particularly after the pilot interview, I conducted the interviews as narrative conversations, described above.

Individual or dyadic interview?

In choosing to focus on the experiences and relationships of people caring for a dying partner, I had to decide whether or not to directly include the perspective of the ill partner in the study. Morris (2001) discusses the advantages and disadvantages of individual or dyadic interviews with cancer patients and their care providers. She concludes that taking account of inclusion, intrusion, power and difference it is preferable to be responsive to the needs of interviewees in deciding which to use. In this study, the aim was to stand as close as possible to the caring partner and their particular perspective. I judged this could best be achieved through individual interviews. The focus of the study was the experience and identity of the individual at a particular point in their life as they faced losing their partner. The conversations would have been very different in a joint interview as would the data generated. In a joint interview the data would not only be constructed

with the participant and myself but would be a combined narrative from both partners each influencing the other. The couple relationship was an important element in the research but as viewed through the eyes of the caring partner.

It could be argued that a more complete understanding of the couple relationship could be gained by interviewing both partners; in addition the ill partner could have insight into the impact of the current situation on the caring partner's well-being and behaviour. Kendall et al (2009) recommend a *multidimensional* perspective involving separate interviews with each partner and with professional carers to better understand the complexity of relationships and care at the end of life. Forbat et al, in their 2009 study, *Better Cancer Care*, interviewed both partners plus a member of the clinical team; people with cancer could opt to be interviewed individually or together with their partner. Their study addresses the advantages and disadvantages of individual and dyadic interviews. A potential disadvantage of joint interviews is that people could feel constrained about discussing difficulties for fear of upsetting the partner, while a potential advantage is that a fuller picture can emerge from the co-constructed account of both partners and the interviewer. One partner's contribution may encourage further reflections from the other.

A further consideration in deciding whether to interview the ill partner was prompted by the time frame of the study. I decided to focus on this late stage of the couple’s life together because the couple are likely to have already undergone changes in the way they live their life and relate to each other. The caring partner will probably, although not necessarily, be some way along the difficult journey of contemplating the loss of their partner and a future alone. The partners of the participants were in the last few months of their lives and, in some cases, obviously unwell. Two partners died within weeks of the interview. It would have been difficult for me to ethically justify interviewing people at this time. I recognise that many studies in palliative care have included interviews with people who are close to the end of life and that to decide against including them could be considered paternalistic. Gysels, Shipman and Higginson (2008) found that palliative care patients regarded a qualitative interview to be a positive rather than negative experience.

Interviewing ill people about their own concerns, however, is not the same as asking them about their relationship with their partner. Taking all the above points into consideration, I decided individual interviews with caring partners were the most appropriate for this study.

Transcription

Following Riessman (2008) I regard transcription as an interpretive process and opted to do the transcription myself. Riessman describes transcription as inevitably selective and incomplete; what is included or excluded reflects the theoretical position of the transcriber. Because the interview data is regarded as co-constructed, my speech was included in the transcription. I included pauses, emphases, expressed emotion, fillers and repairs, interrupted speech and positive utterances. Although not transcribing the interview in the detail used in conversational analysis, the aim was to represent my account of the tone and nuance of the interview as closely as possible. A transcription protocol can be found in Appendix XV.

The rationale for including journals in the study

In a palliative care setting solicited diaries have often been used to record pain or other physical and emotional phenomena (Midtgaard et al, 2007; Oakley et al, 2012), but less frequently to record the reflections of either patients or family carer providers on their experiences of giving or receiving care. Smith et al (2012) used diaries to encourage family members to give feedback on the in-patient care provided to relatives at the end of their lives. The authors acknowledge that people with positive views may be more inclined to comment but maintain that diary keeping improved the quality of care. Valimaki et al (2007), in a study using diaries with the family care providers of people with Alzheimer's disease, note the positive effects of diary keeping. This was both in learning more about the subjective experience and the meaning making of care providers and in the potential therapeutic effect.

Alaszewski (2006) notes that unsolicited diaries are a valuable resource for researchers wishing to explore the nature of suffering. Milligan et al (2005), in a study using diaries with older adults, identify advantages of this method of data collection. It is participant led, can access highly sensitive areas, can provide superior data to interviews and questionnaires and can capture the impact of events over time. Several writers, for example Wright and Cheung Chung (2001) and Lowe (2006), have highlighted the potential therapeutic benefits of writing about emotional experiences. A potential disadvantage of journals is that some participants could find them burdensome, particularly when their partner is dying.

There is a rich tradition of illness narratives in which writing is used to describe and give meaning to life when suffering from a serious illness. (Kleinman, 1988; Mattingly and Garro, 2000). Other writers, for example Dansie (2012), have used a journal to record the personal experience of caring for a friend at the end of life. Bingley et al (2006) conducted a review of published and unpublished illness narratives written since 1950 by people facing death from cancer and other diseases. They highlight the importance of the writing in making sense of dying and in communicating needs to others. Unlike the Bingley study, which focused on existing material produced spontaneously, the participants in this study were responding to my request to keep a journal and their writing was inevitably influenced by the conversation in the interview, the instructions for writing the journal and my relationship with them. Penn (2001) described the benefits of writing for individuals and couples in chronic illness. It offers a way of breaking the silence around the illness and rehearsing what has not yet been spoken aloud.

I included journals to produce a different kind of data. The interviews were co-constructed by the participant and me. Although the participant was encouraged to tell their story their own way, the conversation was taking place because I had instigated it and the participant was responding to my questions and feedback. The journals were a step removed and participant led. Keeping a journal constructs a written self alongside constructions and reflections of everyday life and relationships.

Narrative analysis

Narrative analysis was chosen for the interviews and journals because it allows a sustained focus on each participant's evolving story and identity, within the context of their life and relationships, before attempting to draw comparisons across narratives. Key influences from the narrative field include Riessman (2008) and Frank (2010); both have used narrative analysis to study life stories which have been disrupted by serious illness. Their approaches are a good fit for this study.

What is narrative?

Riessman describes the many forms of narrative in our lives including myths, legends, history, literature, drama, cinema, artwork, photos, biography, songs, memoirs and journals. Although narrative is everywhere, the author warns against overuse, not all talk and text is narrative; narrative requires a sequenced storyline, specific characters and context.

Neither Riessman (2008) nor Frank (2010) draws a firm distinction between story and narrative. This is in contrast to other authors; Paley (2009), for example, argues that while all stories are narrative, not all narratives are stories. He describes the terms as being on a continuum: the point at which a narrative can be called a story is when it can be said to have a *teleogenic plot*, described as when the end of the story informs the beginning and shapes the middle. Gunaratnam (2009) observes that academic literature tends to use *narrative* while practitioners are more likely to refer to *stories*. Squire et al (2014) describe stories being more concerned with content, the *what* while narratives are concerned with the *how* and *why*. Like Frank and Riessman, Squire et al opt to use story and narrative interchangeably. I have done the same in this study, in part to avoid repetition.

Riessman (2014) emphasises the importance of attending to both the *small story* and the *big story* in narratives. Jovchelovitch and Bauer (2000) identify two dimensions in story-telling, the chronological, (sequential episodes) and non-chronological which configures events into a whole, a plot. The plot integrates small stories into the big story where they become meaningful. Thus, the authors argue, a narrative does not just list events but links them in time and meaning.

A brief history of narrative studies

Stories have always been with us and informed our lives. Historians and anthropologists have used stories to gather information and document lives throughout the twentieth century. Key theorists in the narrative field include Ricoeur (1984) and Bruner (1986) who describes narrative as essential to the way we describe and emplot our lived experience.

Riessman (2008), drawing on the work of Langellier (2001), identified four movements which shaped the increase in narrative studies. They include: critiques of realist epistemology and positivism in the social sciences, the proliferation of memoirs, identity movements (such as feminism, civil rights and equality for sexual minority groups) and, finally, the increase in therapy of all kind. Chase (2005) identified Labov and Valetzky (1967,1997) as key figures in the development of narrative analysis. These authors viewed everyday narratives as comprised of linguistic structures which serve specific communicative purposes.

Performativity and the dialogic self

Both Riessman and Frank cite Goffman (1969, 1974) and Mishler (1986, 1995) as important influences in the development of the analytical approaches described below. Goffman (1969) introduced the concept of performativity in social interactions, so transforming the understanding of identity. He suggested that people stage different performances of themselves in different situations and talk does not merely give information, it is a presentation of the self for others, thus identity is constructed in dialogue. Butler (1990) has been

influential in her work on the performance of gender. Mishler (1986) emphasised the co-constructed nature of interviews and the importance of owning the researcher's role in transcription and analysis. He described the concept of the *dialogic* or *narrativised* self arguing that if the self is constructed through continual *story-telling,* the context becomes critical in identity. Identities are discursively constituted, rather than a stable self being reflected in language.

What does narrative do?

Frank (2010) examines the capacities of stories. Socio-narratology is concerned with how the story casts its characters and what this represents to the groups to which they belong. Stories can make a particular point of view compelling and can display and test character. Like Mattingly (2000), Frank comments upon the suspense of stories, they hold our attention because we do not know the outcome. Stories have resonance; they may be echoes of or additions to other stories and can change in different contexts. The meaning of stories is not fixed but may be interpreted and responded to in a number of ways. Frank states that stories have an inherent morality: they can inform our sense of good and bad and how to behave. Stories have the capacity for truth telling; something original comes into being for the first time in a story, stories become true as they are told. Like Goffman (1969) and Riessman (2008), Frank emphasises the performative nature of stories. Storytellers are always performing, shaping a story in anticipation of the response of an audience..

Both Riessman and Frank emphasise the importance of identifying the *work* of a narrative. Riessman identifies the purposes narratives can serve for individuals and groups. Narratives can help us remember: by accessing and reconstituting fragmented or unbearable memories they help us to make sense of the past. Narratives can be used to argue a case and to persuade an audience. A narrative can draw the audience into the world or perspective of the narrator. Stories can entertain or mislead. Finally, narratives can be used to mobilise people into action for social change. In this study I examine the work that participants' narratives do.

Riessman states that her own research (2000, 2003) which has often focused on biographical disruptions, is built around the meaning-making function of narratives. Events such as illness or divorce can disrupt the expected flow of lives and individuals use stories to make sense of their experience. Interrogating the stories reveals how we seek to order and demystify life events to find coherence across the past, present and imagined future. In my study, focusing on the life disruptions precipitated by a terminal illness, the meaning-making function of narrative will be a key element. Riessman cautions that narrative must always be considered in context; it happens in a particular time and place and is informed by current discourses. It is designed for particular audiences. Although addressed to me, the participants in the study may also be addressing an imagined audience, other family members or the wider public.

Frank (2010, pp46) identifies the primary work of stories as *making the earth habitable*. I understand this to mean stories make order out of chaos by imposing a coherent sequence, so making life more manageable. Stories teach people what to seek out and what can be ignored, what to value and what to hold in contempt. Frank maintains that stories themselves can both injure, for example by being coercive, and cure, perhaps by repairing the narrative damage caused by a serious illness He claims the work of dialogical narrative analysis is to increase the possibility of cure while minimising that of injury. This may be aided by opening stories up to other stories and alternative interpretations. The author states that stories teach us who we are. Like Mishler (1986), he suggests that rather than narrative identity being fixed, the reciprocal processes of narratives make several possible identities available to us.

Drawing on the work of the philosopher Louis Althusser (1971), Frank introduces the concept of *interpellation* to describe how stories can call upon someone to acknowledge and act upon a particular identity, to respond in a particular way. He raises the question of why certain interpellations should be more compelling than others and uses the term *narrative habitus* to describe the repertoire of stories which form and shape our lives and become our

second nature. Habitus could be considered comparable to the concept of cultural templates which inform our behaviour and interactions but which we may not be aware of until they do not fit with our current experience.

Both Riessman and Frank highlight how stories can work to bring people together by highlighting shared beliefs and common aims and perhaps by persuading those who are uncertain to participate. Stories can enable groups to assert a common identity, whether in political movements, subjugated groups within society or even companies seeking to develop a common ethos to strengthen their brand.

Dialogic/performance analysis (DPA)

One of the approaches I have drawn upon for this study is Dialogic/Performance Analysis (Riessman 2008). This method aligns with my epistemological position. The focus on performance of identity is important in addressing my research question. Riessman describes this approach as incorporating elements of both structural and thematic narrative analysis but adding other dimensions. It interrogates how talk is dialogically produced and performed and focuses on contexts. These include the setting, the influence of the researcher, the social circumstances and the interpretation of narrative. This approach asks who a narrative is directed to, when, and why and for what purpose. She claims a story is co-produced in a complex dance between teller and listener, speaker and setting, text and reader and history and culture. The researcher is an active presence in the text. DPA draws on other models which emphasise the importance of interaction and performance (Goffman, 1969).

Riessman explains that we constantly compose impressions of ourselves, projecting a definition of ourselves in the world which we test out and negotiate with others using speech and non-verbal communication. Being a performance does not infer the projected identity is inauthentic. Identities are constructed in performances for others and therefore the response of the

listener is an important element in the story. This concept has been an important element in this study.

Riessman describes how literary theory informs DPA, in particular citing the work of Bakhtin (1981). Bakhtin situates all speech in the "I-thou" relationship; form and meaning emerge between people in a particular social and historical context. He suggests that every text contains multiple voices, historical and political discourses, beyond the author's voice. Narratives are multi-voiced and the author or speaker does not have authority over the meaning. All words are saturated with meaning from previous usage and analysis is never from a neutral position. Riessman states that these ideas are important because they demonstrate the need to note any gaps or indeterminate sections in personal narratives and to listen beyond the participant, to be aware of other voices and other discourses. In this study canonical narratives and previous narratives drawn on by participants will be considered in the analysis.

Riessman's interpretive techniques for DPA

Riessman's analyses using DPA incorporate both thematic and structural (or discursive) elements but the primary focus is the performance of identity within a narrative. She notes the way different identities are constructed in an interview, taking account of for whom and in what context. She identifies how a story is told and takes note of how the teller positions the listener. Riessman demonstrates how past actions can be performed as if in the present and notes the effect this enactment has in engaging the listener.

Riessman analyses linguistic (structural) elements of a narrative and shows how direct speech may be used to bring immediacy to a story. She notes how repetition may be used to make a point and how shifting tenses can work to increase vivacity or enhance a sense of agency in an account. The thematic analysis described by Riessman refers to the identification and analysis of *narrative* themes, in contrast to the more widely used meaning in qualitative methodology which refers to identifying, analysing and reporting patterns

within data (Braun and Clarke, 2006). Language is not taken at face value but is interrogated in context.

Riessman emphasises the importance of intersubjectivity and reflexivity in the dialogue between the researcher and the researched, text and reader and knower and known. She views a research study as a story itself, open to the interpretation of the reader. There is a focus on situating the individual interview within the broader political and social context. I discuss how I have applied Riessman's interpretive methods in the *Method* section.

Dialogical narrative analysis (DNA)

Frank (2010) describes his approach to analysis as Dialogical Narrative Analysis. The purpose of DNA is to study how stories give people the resources to consider who they are and how they connect to others, how all the capacities of stories described above come into play in a particular narrative. Frank (2010, pp 75-82) identifies a number of questions to begin the work of analysis, including: *What does the story make narratable? Who is holding their own? What is the effect of people being caught up in their own stories and other peoples? What is the force of fear in the story, and what animates desire? How does a story help people to remember who they are?* In my study I used these questions to inform my thinking rather than answering them directly

Frank describes interpretation as inherent in storytelling; both teller and listener constantly interpret one another. DNA seeks to engage in ongoing dialogue with a story rather than to pass judgement upon it. Like Riessman, Frank identifies Bakhtin (1981) as an important influence. Although Bakhtin was analysing fiction but the stance towards the character and participant is similar. Three considerations are highlighted: the importance of not *finalising* a participant, speaking *with* rather than *about* them and *claiming no privilege of interpretive authority.* DNA may add to the story without saying something the teller could never have said. These concepts are important to me in my aim to be an ethical researcher.

Cross-narrative analysis

Both Riessman and Frank begin analysis with a sustained focus on the individual narrative before looking across narratives. I use two methods of cross-narrative analysis; a thematic narrative analysis informed by DPA, as described by Riessman (2008) and a typology, as described by Frank (1995, 2010). I consider these methods to be complementary. The analysis of narrative themes identifies a broad range of themes across the narratives while the typology focuses on the narrative types most prominent in the individual analyses. The analysis of narrative themes allows examination of some important aspects of the data not covered by the typology. Frank describes how DNA can enhance individual stories. By hearing multiple stories about similar experiences, a single story can be opened to other possibilities. An experienced analyst can link stories in a way that is a potential resource for participants and fragmented stories can be given coherence.

Frank's typology

Frank (1995, 2010) defines a *typology* as a group of core *narrative types*. The three types he identifies are: *the restitution narrative, the chaos narrative* and the *quest narrative.* Frank (1995, pp 77) summarises the restitution narrative as: *Yesterday I was healthy, today I'm sick but tomorrow I'll be healthy again.* In these narratives the illness is temporary, former function will be restored and the identity is intact. In contrast, the chaos narrative lacks narrative order and holds no hope of getting better. Life is radically and irreversibly altered and the future is unpredictable, the self of the sufferer is submerged in the illness. The quest narrative accepts illness but seeks to use it: illness is the journey that becomes the quest, new experiences lead to a new identity and valuable lessons have been learned which can be passed on to others. Individual narratives may include one or more of these archetypes.

Frank (2014) enlarged upon his typology to include other possible embedded stories in illness narratives; including *resentment* stories, *trickster* stories, in which the protagonist is initially taken in but the trickster is then punished, *transcendence* stories, which include moments of grace, when someone is held or helped by something beyond the self, and *mirroring* or *borrowed* stories in which stories which reflect the teller's own are adapted and used. As discussed in the literature review, other writers (e.g. Hydén, 1997) have described alternative narrative typologies. Although Frank's typology refers to the experiences of an ill person rather than someone caring for them, elements resonated with the narratives in this study.

Reflexivity and the choice of methodology

The methodologies I have chosen are intrinsically reflexive and acknowledge the subjectivity of the researcher in constructing data. In my choice I was influenced by the philosophy informing them. I find in Riessman's (2008) work, however elaborate the analysis, the personhood of the subject shines through, she brings humanity to the endeavour. I admire the clarity of her writing and her ability to present complex ideas about narrative in an accessible way. In Frank's work (2010) he emphasises the importance of treating the participant with respect, seeing them as the expert on their own life and story. He warns against using interpretation as a way of finalising or suggesting that the interpretation is all the person or the story is. He suggests speaking with rather than about a participant, standing alongside them. All of these chime with my preferred stance as a researcher.

Sample size

The literature searches I have conducted into sample size for narrative analysis studies indicated there is no definitive answer to the question of how many interviews can be considered sufficient. Baker & Edwards (2012) addressed this question to researchers across various qualitative modalities and the overwhelming response was that it depends upon the research

question, the theoretical framework, the aim of the study and practical considerations. Several of the respondents highlighted the point that in some circumstances a single case study could be sufficient. Guest et al (2006) suggest that no new theoretical insights are likely to be emerging beyond twelve cases.

In narrative analysis the quality of the sample and the depth of the analysis may be more important than the quantity, and the strength of the individual narratives may be more important than commonality between them. Some writers, for example Riessman (2008) and Emerson and Frosh (2009) focus on single cases to illustrate their methodologies. Riessman (2008) and Mishler (1996) make the point that both in medicine and the social sciences there is a tradition of knowledge generated from case studies.

My aim was to have a sufficient number of participants to do justice to the topic and to have a sufficient number of people to allow for some diversity and to take account of the fact that some participants may drop out of the study, perhaps due to the death of their partner. The possibility of two sets of data from each participant (the interview and the journal) was considered. I aimed to recruit ten to twelve participants. After eighteen months, eight people had been referred, two withdraw before interview because of their partner's condition and other family reasons, leaving six in the study. However, there was some diversity in the sample and the participants provided rich and varied data, including three journals. I would argue that the number, although less than planned, is sufficient for this study and has enabled me to focus in more depth on each narrative than would have been possible with a larger number.

Participants have chosen to take part in the study and thus may not reflect the range of experiences of people caring for a dying partner. The reasons why an individual may opt to tell their story, in a particular way at a particular time, while another may decide not to will be explored more fully in the discussion chapter. It is possible that referrers may have been selective in the people they recruited to the study *gate-keeping*; the less articulate or those

considered more vulnerable could have been excluded (Hudson and Payne, 2009).

Ethical Issues

I was aware from the outset that the topic of this research study is of particular sensitivity. The participants were likely to be at a difficult point in their lives, they could be over-burdened, exhausted or in distress. Some could find talking about their past and present lives and the relationship with their partner painful. I hope that, as an experienced psychotherapist, I conducted the interviews in such a way as to minimise distress for the participants. In this section I summarise the ethical approval processes to which the study was subject. I examine the issue of informed consent for the study, and clarify how confidentiality was ensured. The risks, burdens and benefits to participants are assessed.

Ethical approval

Ethical approval for the study was obtained from the following bodies.

- The National Research Ethics Service, Camden and Islington
- North West London Research Governance Unit
- The Tavistock Research Ethics Committee
- UEL Ethics Committee (granted retrospectively to meet altered requirements)
- The Research Ethics Committees of the hospices recruiting participants for the study

The process of obtaining approval from the various bodies was protracted and complex. The Integrated Research Application System (IRAS) committee required ample evidence that participants were not coerced into taking part and that they would not be harmed by the process. The first application was not approved. Amendments were suggested, including:

- Minor changes to the recruitment process
- Further clarification of contingency plans should a partner die during the study or wish to withdraw
- Further clarification of contingency should I have concerns regarding the safety or wellbeing of a participant or partner
- The committee suggested the partner should be consulted regarding participation in the study. (This issue is addressed in more depth under *informed consent*)
- Addition to the supervisory team to include expertise in the field

The application was amended, as were the information documents for participants and referrers (Appendices II, III, V, & VI). A favourable opinion was obtained from IRAS in April 2012 (Appendix XIV). This was followed by approval from North West London Research Governance and finally by hospice ethical committees. None of these required significant changes, although minor amendments were made to suit each hospice's specific requirements.

Informed consent

Schofield (2014) defines two principles underpinning informed consent in research: consent should be fully informed and freely given. The informed consent process aims to safeguard the wellbeing of individuals and protect them from harm, in addition to protecting their autonomy. Appelbaum and Roth (1982) define the key elements of informed consent as full information, voluntary participation and capacity to make a decision. Schofield (2014) identifies the elements necessary for informed consent to be considered valid. Information about the study must be given and understood; it should be accessible and comprehensible to the individual. Potential participants should be clear about the purpose of the research and any risks it may involve. Consent should be freely given without coercion, taking account of any power imbalance between researcher and participant. A participant may withdraw from a study at any point without an impact on any care they may have been

receiving (Flory, Wendler and Emanuel, 2007). The final element raised by Schofield is competence, addressing whether the potential participant is capable of making an informed choice about research participation.

In this study I have observed the tenets of informed consent. Information about the study (Appendix II) and the consent form (Appendix III) were given to participants by hospice staff before the interview so that they could be read and, if wished, discussed within the family. The information was clear, concise and readable and I was explicit about my own role in the study. It was made clear that participants were under no obligation to take part in the study and that they could withdraw at any point without any impact on services they were receiving. Before the interview I went through both documents with participants and addressed questions or concerns regarding the study before they signed. The issue of capacity was considered but did not prove problematic in this study. Participants were referred by hospice staff who knew them and would have been aware of any difficulties concerning function.

Usher and Arthur (1998) and Dewing (2007) redefine informed consent as a process that runs throughout treatment or a research project. In this study process consent was addressed by checking if an interviewee wished to proceed during the interview and being alert to any signs of distress or fatigue. Following the interview I made it clear that the participant had a choice about keeping a journal and in follow-up phone calls and visits I rechecked that the participant was still agreeable to my using data and quotations from the interview

The concept of informed consent is complex because neither the participant nor I could predict the impact participation would have on them at the time. I addressed this explicitly in the information sheet. A complicating factor was whether a participant's partner should be consulted about the study. Hudson and Payne (2009) view family carers as self-directed individuals who can decide for themselves whether or not to participate in research. Other studies (Forbat et al, 2010; Harding et al, 2012) involving interviews with carers but

not patients did not require a patient to give signed consent for a relative to take part. I believe that in entering a couple's home as researcher and a guest, there is a duty to treat both partners with respect and consideration; it is not ethical to act in a way which could cause discord between couples. Thus, I offered to meet the partner and asked the interviewee if the partner was aware of and agreeable to the study. I did not, however, ask the ill partner to sign a consent form because I believe this to be unnecessary and potentially burdensome to them.

Confidentiality

Throughout the study, all efforts were made to ensure the confidentiality of participants. Contact information was kept to a minimum and stored securely. All interviews were anonymised as they were transcribed. All names and some details were changed. Handwritten journals were transcribed and the originals returned to the participants.

Only I had access to personal data during the study. Hospice teams were aware of the identities of participants but no individual information was shared with them and feedback about the study was anonymised. Data shared with supervisors or with colleagues in data analysis workshops was anonymised. Computer files relating to the study do not contain personal information. At the end of the study computer files will be deleted and paper records shredded. All participants agreed to quotations being used but care was taken to ensure individuals were not identifiable from them.

Limits of confidentiality

Participants were made aware that confidentiality would only be breached in the event of a participant disclosing a criminal act or intention to commit a criminal act or if I were concerned about the safety of a participant or their partner. Please see *Information for Participants* (Appendix II) and *Consent Form* (Appendix III). An example of how this issue was addressed in practice is given below.

Risks, burdens and benefits for participants

Lee and Renzetti (1993) highlight the issues concerning sensitivity, which they define as anything which could bring risk or cost to the participant or researcher. Addington-Hall reviewed research participation for palliative care patients and their families and highlighted both the importance of research and the importance of assessing the impact of it. Corbin and Morse (2003), in a review of sensitive research interviews, maintain that unstructured interactive interviews, which leave most control in the hands of the interviewee, are no more of a risk to participants than everyday life and, when conducted with sensitivity and guided by ethics, are likely to benefit both researchers and participants. Watts (2008) concludes that, while interviewing people who are dying or bereaved for research purposes could be considered problematic, interviews could bring about positive cathartic effects. Pessin et al (2008) assess the impact of interviews on hospice patients thought to be within two months of death. Most of the sample found the experience beneficial, citing social interaction, an opportunity to discuss their illness and a sense of contributing to society as the most beneficial factors. The few who found the interview burdensome attributed it to the length of the interview. The authors conclude that research participation can be beneficial to people who are terminally ill.

Talking about life and relationships at a time when one's partner is terminally ill can be upsetting for participants; some of the participants in this study expressed sadness or were tearful during the interview. Overall, however, participants reported finding participation in the research to be a positive experience, several describing it as *cathartic.* Dickson-Swift et al (2007) report similar findings. At a time when attention and energy are understandably focused on the ill partner, it could be a relief to have someone listening closely to the care provider's story, bearing witness to their experiences and concerns.

I was aware that a prolonged interview could prove inconvenient or burdensome and that it was necessary to be flexible, if necessary completing the interview at another time. Issues of burden are discussed by Pessin et al (2008). It was likely that some participants would find it difficult to give the time and attention to completing a journal. I made it clear that they were under no obligation to write one. There was a balance to be struck between encouraging what could be an important aspect of the study and not putting on pressure which could make the participant feel uncomfortable about not completing it. Three participants completed a journal and three did not.

Self-reflexivity

Self-reflexivity is widely accepted as a central tenet of systemic practice and qualitative research (Burck, 2005, Riessman, 2008, Emerson & Frosch, 2009) If it is accepted that data is co-constructed, it follows that the researcher's position and contribution should be acknowledged and examined. Burck (2005) emphasised the importance of taking account of context, including the research relationship and power differentials; what each has at stake in the research process is also important. The ways in which a participant may be similar to or different from a researcher including class, gender, ethnicity, age, culture and sexual orientation should also be considered. Findlay (2002) reminded us that subjectivity is an opportunity rather than a problem and suggested guidelines for promoting self-reflexivity in research. These include introspection, intersubjective reflection, mutual collaboration, social critique and discursive deconstruction. She defines the functions of self-reflexivity in research as acknowledging the impact of the researcher, increasing insight, revealing the unconscious motivations and biases of the researcher, enabling the evaluation of the research method and outcomes and enabling the public scrutiny of research.

Dickson-Swift et al (2007) examined the impact of conducting qualitative research on researchers and highlighted issues which can arise for the individual and in the research relationship. The authors discuss the impact on

the researcher of hearing *untold stories* (which may be particularly hard if they resonate with a researcher's own experience), negotiating the minefield of self-disclosure and experiencing feelings of guilt or vulnerability. They recommend that researchers have access to fellow professionals, a peer group or more formal supervision to provide a supportive framework.

As discussed above, my choice of topic for this study was influenced by professional and personal experience. I have a longstanding professional and research interest in how partners respond to biographical disruption and the impact on identity and the couple relationship. My experience as a family care provider had a profound effect on me personally over the period of my twin sister's illness and death. There are many differences between losing a partner and losing a twin, but may be some similarities. In both you are losing someone with whom you have journeyed through life, the relationship has been part of the context of your evolving identity. Both my professional and personal experience contributed to my sense that the voice of the caring partner deserved to be heard. I was aware that this would impact on my study.

As Fredman (2007) observed, it is important to examine one's own position regarding death and how it is dealt with within the family in order to be sensitive to the experiences and beliefs of others. I grew up in a medical family where discussions of illness and death were common. I shared the belief that transparency was desirable and secrets were not. This was mostly reinforced by my training and practice as a psychotherapist. Over the years, however, I have developed a somewhat more nuanced understanding of openness, taking more account of timing and cultural considerations.

I believe there are potentially both positive and negative aspects to choosing a research topic close to personal experience. The researcher is likely to be more aware of the multiple aspects of a subject, is more likely to be attuned to the experience of the participant and may be seen by the participant as someone who understands their position. At the same time, there could be a danger of making assumptions that another's experience is similar to one's own, or of seeking out reflections which mirror one's own, leading to over-

identification with the participant. For example, in my family the months leading up to my sister's death were, although sad, a special period when we spent valuable time reviewing and even celebrating our lives together. I was aware that I was hoping to find this in my research and had to remind myself this would not fit with everyone's experience and I should be alert and sensitive to alternative stories.

Managing subjectivity

In addition to individual psychotherapy, I used a number of methods to reduce the likelihood of my own experience impacting too forcefully on my research. These served the dual purpose of protecting me from distress when narratives resonated with my own. Before starting my interviews, I was interviewed by a colleague using the same interview guide used with participants. This assisted me to critique my questions and increased my awareness of my own narratives, thus reducing the likelihood that I would attribute my agenda to participants. An example of this was my perception that my sister's secondary tumours should have been picked up earlier by clinicians, something I had not explored in depth with my sister because of her need to have faith in them. This proved to be an issue for several of the participants and it was important that I should not overvalue it in the light of my own experience.

Noting my reflections in a research diary, particularly following an interview, was helpful in appreciating the emotional timbre of the interview and my part in the knowledge production. Following each interview I had a *de-briefing conversation* with my partner. This did not concern the content of the interview but helped me process my emotions in relation to it. I discussed my interviews with my supervisors and peer group at the Tavistock and presented my data and analysis several times at data analysis sessions and symposia (Dickson-Swift et al, 2007). These experiences were critical in helping me to understand my own stance, bringing to awareness my position with particular participants and issues I had undervalued or even completely missed. I fully accept the inevitability of my experiences, opinions and style colouring the research, the interviews are co-constructed with each participant and the

analysis is my interpretation. These strategies, however, increased my self-awareness.

Relational reflexivity

Relational reflexivity, as applied to the therapeutic relationship, has been defined by Burnham (2005):

> *"The intention, desire, processes and practices through which therapists and clients explicitly engage one another in coordinating their resources so as to create relationships with therapeutic potential. This would involve initiating, responding to, and developing opportunities to consider, explore, experiment with and elaborate the ways in which they relate."*

In conducting this study I gave consideration to my relationship with participants and how this impacted on the research from the outset. In the information I gave to participants before the interview, I explained that in addition to being a family therapist I had personal experience of end-of-life care. Some were curious about this, others were not. The complexities of self-disclosure are addressed by Dickson-Swift et al (2007). While often helpful in terms of forming an alliance, sharing too much personal information could leave the researcher feeling exposed and the interviewee burdened. Other than a brief mention on the information sheet, I did not spontaneously offer further information about caring for my sister but, if asked, I replied honestly. At the end of most of the interviews, usually over a cup of tea, some participants asked me more about myself and my family and this acted as a useful *winding down* of what had been an intense experience.

I was aware of the difference between the position of therapist and researcher during the interviews. Where, as a therapist, I might have challenged an assertion or invited a different perspective, as a researcher I was more inclined to accept it, although possibly asking for elaboration. The context of a one-off interview also organised the relationship, it would not be ethical to

purposefully probe areas of difficulty which might leave a participant feeling exposed when there was little follow-up. In common with some of the researcher/ participants in the Dickson-Swift study, at times during the interviews I was aware of feeling somewhat guilty that someone should open up to me so much and then never see them again but, as the authors observed, a participant may find it liberating to open up to someone they will never see again, this was expressed by one of my participants.

The stance I adopted with participants could best be described as *standing beside:* listening closely to their story and trying to appreciate their perspectives on their life, relationships and experiences as accurately as possible; this is the position favoured by Frank (2010). I did not take the position of the expert and tried not to judge or categorise. Moving away from a question and answer format towards eliciting a story facilitated this position.

I was conscious of feeling protective of my participants (Dickson-Swift et al, 2007) and this was usefully highlighted for me in a data analysis session. It was observed that when anyone suggested a more negative attribution to one participant's story, I would leap to her defence, asserting, *"She was not self-pitying!"* While this may speak to my own relationship to self-pity, it also connects to my relationship with Valerie, the participant. I had such respect for her bravery and stoicism that it was inhibiting me from taking a more nuanced perspective on her position.

Relational reflexivity is a helpful framework for considering the study's recruitment difficulties. Liamputtong Rice and Ezzy (1999) discuss gratitude in research contexts and recruitment and how this might impact on data collection. In this study recruitment took over fifteen months and consequently, when a participant was referred and agreed to be interviewed, I was conscious of feeling considerable gratitude towards them. Although I believe that participants should always be treated with respect, my gratitude could have resulted in too much deference or a reluctance to acknowledge more negative aspects. From both an ethical and personal perspective I tried to ensure the interviews were not an overall negative experience for the

participants. I included questions which invited more positive reflections and valued the participant.

*

In this chapter I have described the methodology of the study; the following chapter provides a detailed description of the method, from recruitment through data analysis.

Chapter 4

Method

This chapter describes how the study was conducted, including all aspects of recruitment, a brief description of the participants, the pilot study, the interviews, the journals, follow-up contact and data analysis.

Recruitment

The recruitment process was in compliance with the wishes of the Integrated Research Application System (IRAS) committee. Participants were recruited through hospices whose services have contact with caregivers meeting the inclusion criteria (see below) for the study. IRAS recommends that the initial approach to a potential participant be made by someone other than the researcher. Working with a hospice ensured that the approach was made by someone familiar to the participant and minimised intrusion. I had hoped to find enough participants through one hospice but, when few referrals were forthcoming, additional centres were contacted. Ten hospices were approached and three participated in recruitment. Detailed written information about the study was provided for hospice staff in the documents, *Information for Referrers* and *Recruitment Protocol*, (Appendices V and V1).

The recruitment protocol

Hospices decided how to approach participants; two chose to recruit through Clinical Nurse Specialists working in the community and one through hospice support groups for carers. Hospice staff identified potential participants and informed them about the research, using the flyer which briefly describes the project (see Appendix I). If a participant showed an interest in the study, the staff member provided further information in the form of the *Information for Participants* leaflet (Appendix II) and the *consent form* (Appendix III).

The information leaflet was designed to introduce myself and the study to potential participants in a clear and understandable way. If they agreed to participate, the nurse or social worker gained permission to pass on contact details to me. In the first phone contact, I ensured that each participant met the inclusion criteria for the study. It was emphasised that there was no obligation to take part in the study and participants could withdraw at any point without it affecting any services they or their partner may be receiving. If the participant wished to proceed with the interview a time and place was agreed. The referrer was informed of the interview.

Inclusion and exclusion criteria

Recruitment was initially restricted to people who were currently caring for a partner with late-stage breast or prostate cancer. These diagnoses were selected because of the high incidence in the population and in order to include men and women in the study. The term *late-stage* was chosen because, while usually referring to metastasised cancer, it is less restrictive than defining a specific cancer stage and is more understandable and less jarring to potential participants than other terminology. Late-stage was defined, in conjunction with referring hospices, as someone likely to be in the last six months of life, although it is usually impossible, or at least unwise, to be specific about time-frames when someone is dying of cancer. In response to low recruitment the criteria were extended, first to include other cancers and later to include other terminal prognoses. In the event, all the referrals were for partners of people with cancer.

I chose to focus on people at this stage because the caring partner would probably have had time to process and reflect on changes in their life and relationship and may be actively involved in various aspects of care. Cancer was chosen to have some conformity across the sample and because the disease trajectory for terminal cancer is somewhat more predictable than for some other terminal conditions. This issue is discussed by Murray, Kendall, Boyd, and Sheikh (2013). Participants were required to have been living with

their partner for ten years before the onset of illness. Same sex couples were included although none were referred.

Excluded from the study were people unable or unwilling to participate and anyone for whom participation would be unduly burdensome. I aimed to recruit participants from diverse cultural backgrounds. Those who did not speak English fluently were not excluded, contingent upon finding appropriate interpreters and translators, but none were referred.

Problems in the recruitment process

Despite positive responses from participating hospices to the study, referrals were slow to materialise. I contacted a staff member within each hospice regularly by email to remind them about the study and encourage referrals. Hospice staff cited the following reasons for lack of referrals:

- Potential participants were unwilling to be interviewed or were concerned about upsetting the partner.
- Partners had a diagnosis other than cancer.
- The carer was not the patient's partner.

In response to this feedback I extended the inclusion criteria to include other terminal diagnoses. The following factors may also have influenced recruitment:

- Hospice staff were busy and stressed, research recruitment may understandably have been a low priority.
- The staff who had initially agreed to the agency's participation, (managers, consultants), are not those who would be recruiting and staff who are in contact with potential participants may not feel ownership of the recruitment process.
- Staff may be protecting their clients from upset. This practice, known as *gate-keeping*, has been described by Hudson and Payne (2009).

I appreciated that hospice staff have other priorities and respected their judgement as to whether it is appropriate to approach a particular individual regarding research participation. Throughout my contact with each hospice I was aware of the fine line between keeping the idea of the study alive with the hospice team and becoming a nuisance with overzealous reminders.

The participants

Eight potential participants were referred to the study; two withdrew before being interviewed due to deterioration in their partner's health and other family issues. There was some diversity within the group of participants. A full description of each participant is given in Chapter 5, *Individual narrative analyses.* All names and some details have been changed.

Name	Age	Ethnicity	Employment	Children
Anna	67	White British	Retired	Yes (adult)
Brian	63	White British	Retired	Yes (adult)
Colin	65	White British	Retired	Yes (adult)
Deidre	54	Irish	Sick Leave	Yes (adult)
Estelle	43	Madagascan	Employed	Yes (young)
Valerie	71	Anglo-French	Retired	No

The Pilot Study

The first referral was considered to be a pilot but was included in the data analysis. The method was similar to the other interviews except that I constructed a genogram at the start of the interview and made more reference to the interview guide. I decided to omit the genogram because it involves questions from the interviewer and answers from the participant and can establish a pattern of communication which could discourage a participant

from telling their story in their own way. The details of family members and relationships emerged naturally during subsequent interviews.

The Interviews

Establishing a context for the interview

Most participants preferred to meet in their own home, one was interviewed in the lounge area of her sheltered housing complex. The advantages of interviewing in the participant's home include the convenience for the participant, particularly if they are reluctant to leave their partner for prolonged periods, and that people are likely to be more relaxed in their own space. The disadvantage is that the interviewer has less control of the boundaries of the interview, interruptions are possible and the interview may be overheard by other family members, possibly making it more difficult to speak frankly. In some instances the participant's partner was not in the home at all, in others, the participant had decided upon a private space within the home. For one interview, the interviewee's partner was in an adjacent room with a friend, so privacy was more limited. The implications of this are discussed in the analysis section.

Opening the conversation

Before starting the interview, I checked the participant had read the information sheet and answered any questions or concerns. I asked them to re-read the consent form and sign it. I recorded the interviews using a digital audio recorder. I began each interview (excluding the pilot) with an opening question, for example:

"How did you first become aware that [your partner] was unwell?"

This usually prompted a detailed description of the partner's symptoms, investigations, diagnosis and treatment since they first became ill. Although

the interview was based upon the *interview guide* (see Appendix IV) the conversations flowed naturally from the opening question, with minimal questions and prompts from me. I followed the participant's feedback and conducted the conversation accordingly. Most of the topics in the interview guide were covered spontaneously so the guide was only consulted to ensure there were no major omissions.

Closing the conversation

Before ending each interview, participants were asked if there was anything we had not yet discussed which they thought it was important for me to know. Participants used this opportunity either to introduce another topic, sometimes of a very sensitive nature, or to reiterate a point they wanted to emphasise. I concluded the interview by enquiring how the experience of being interviewed had been for them. Before leaving I discussed whether and how each participant would like to keep a journal. Finally I thanked them for taking part in the study and made arrangements for future contact.

Time frame for the data gathering

The first interview took place in late November 2012 and the final one March 2014. This reflected the recruitment difficulties described above.

The journal

I asked each participant whether they were willing to keep a journal. I emphasised there was no obligation and that I would respect their wishes if they decided against writing one. If willing to try, participants chose a handwritten or email journal. I ran through the journal guidelines (Appendix VII) and emphasised that, although there was no right or wrong way to write it, I would be interested to hear about their day-by-day life and reflections on their experiences, relationships and concerns. I encouraged participants to

write something every day over a three week period and arranged to contact them after one week to review progress.

Of the three participants who kept a journal, two were on paper and one by email. The paper journals were collected after three weeks at the debriefing conversation and were returned to the participants after transcription. The email journal was sent daily as an attachment. I established that I would not be responding to the emails on a daily basis. Becoming a dialogue would have changed the meaning of the journal.

Follow-up contact

The first follow-up phone call was arranged one week after the interview and was kept fairly brief, unless the participant wanted to give an update on events in their life. All participants were asked how they were after the interview and, for those keeping a journal, progress was discussed. The final contact was at the end of the three week journal period and was either a face-to-face meeting or a phone call. The main purpose of this conversation was to ascertain how the experience of taking part in the research had impacted on the participant.

If I had any concerns regarding the wellbeing of any participant I discussed with them how best to address these and would, if necessary, have contacted the local hospice to arrange further assistance. It also allowed me to confirm that participants would agree to me using quotes from the interview or the journal, providing confidentiality and anonymity were ensured. I asked participants if they would be interested in receiving feedback on the outcome of the study and finally thanked them for their participation and wished them well for the future. Four of the debriefing conversations were conducted over the phone and two in the participant's home. Notes were made of the interview soon afterwards and, with the transcript, were used in the analysis.

Transcription

The interviews were recorded and all transcribed by me. Soon after each interview I listened to the whole recording to gain an overall perspective. Notes on interview tone and my immediate response to the interview were recorded. I then transcribed it verbatim, including my speech. A transcription protocol can be found in Appendix XV. The transcription of the pilot interview was returned to the participant by agreement. The paper diaries were copied accurately before returning the original to the participants as agreed.

Data analysis

The chosen methodology was dialogical narrative analysis, informed by the work of Riessman (2008) and Frank (2010). Each narrative was initially analysed individually. The following interpretive techniques were used to organise and interrogate the data, I moved between the steps as one aspect informed another.

Initial reflections

After each interview I wrote field notes. Following the first reading of the transcript, I made notes under the following headings.

- Overall tone and my reflections on the interview and research relationship
- What is missing from the interview? (Frank, 2010)
- What is the participant gaining from the interview?
- What identities are being performed in the interview? (Riessman, 2008)
- What work does the narrative do?
- Follow-up

This helped me to view the interview as a whole. It aided self and relational reflexivity in providing me with an opportunity to consider my part in the

knowledge production and my response to the interview and participant. An example, entitled *Interview tone,* can be found in Appendix XI.

Initial analysis process

On re-reading each transcription, I identified segments of dialogue which illustrated the performance of identities (Riessman, 2008) and other narratives drawn upon. In each interview I identified approximately six categories based upon what was most compelling in relation to the research question and what seemed most important to the participant. I was not seeking commonality across the narratives at this point. To aid reflexivity, some of the analysis was shared with supervisors and peer group for feedback.

The following techniques were used to continue the analytic process, most of the steps were used for most of the cases and examples of each method can be found in the appendices.

Summaries in the voice of the participant

I wrote a summary of each narrative in the voice of the participant. This strategy helped me to appreciate the participant's position, in terms of their experiences and how they were representing themselves in the interview and provided an overall perspective (example Appendix XII).

Summaries in the voices of other characters

This process, described by Frank (2010), opened up stories to alternative perspectives to assist interpretation. The characters were selected based on their importance to the narrative and potential difference in perspective (example Appendix XV).

Letters to the participants

I wrote a letter to participants to explain what I most appreciated about their narrative Frank (2010). The letters, which were not sent, clarified my

relationship with the participant and encouraged a respectful stance. They helped to highlight the most important elements in each narrative and were useful in understanding a narrative in its entirety. (example Appendix XIII).

Letters to the narratives

This strategy (Frank, 2010) explored the work of the narrative and what I learned from it. It described how the narrative affected the reader's perspective (example Appendix XIV).

Completing the individual analyses

Using the above resources, and the identified categories, I began the final stage of the analysis of each narrative. The data was interrogated for content, for how it was produced, by whom, for whom and in what context.

Questions to interrogate narratives

(Informed by Riessman, 2008 and Frank, 2010) These questions informed the construction of all of the documents described above and were a valuable resource throughout the analytic process.

What is the work of the narrative?
What identities are being performed in the narrative?
What case is being argued?
What is the meaning-making function of the narrative?
How does the narrative draw the listener / reader in?
How is gender being performed?
How are cultural templates represented?
Why now?
For whom?
How is narrative being co-constructed?
What is the context and how does it impact upon story?
How does the "little story" connect with the "big story?"
What other stories are being drawn upon?
What is missing from the narrative?

How do current experiences fit in the context of the participant's life and relationships?
How is language being used in the narrative? What does it do?
What narrative identities are privileged / suppressed / excluded?
How is the couple narrative represented?
How does it intersect with the individual narrative?

The interviews produced numerous examples of the construction and enactment of identity. A discursive approach was used to highlight the work of the narrative, for example, to interrogate how direct speech was used in the interview. I analysed each journals after the interview, noting similarities and differences and exploring the meaning of the journal for each participant. I wrote a summary of each case, drawing together the most significant elements from both interview and journal.

Cross-narrative analysis

When the individual analyses were completed, I looked across the narratives to identify commonalities and differences. I have approached this from two aspects*, narrative themes* and a *typology* of narrative types as described by Frank (2010).

*

In this chapter I have detailed the method employed in the study. In the following Chapter I present the analysis of the individual narratives.

Chapter 5

Individual narrative analyses

Introduction

This chapter contains the individual analysis of the six interviews and three journals. Each analysis begins with an introduction to the participant and a short description of the interview. Each narrative is organised into subsections demonstrating the performance of identity and other important narrative elements of the interview. Where the analysis of the journal overlapped with that of the interview it is included in the main analysis, otherwise it is analysed separately. Each narrative concludes with a summary.

Anna

(The Pilot Study)

Anna (67) and Anthony (79) are a white British couple who have been married for 35 years. Both were previously married and divorced; both have children from previous relationships and two adult children from this marriage. They are in regular contact with all their children and grandchildren. Anna was a mental health professional and Anthony an author. Anthony, who had previously been in excellent health, was diagnosed with terminal cancer 14 months before the interview. He was given an expected life span of 4 to 5 months but continues to lead full and active life.

The Interview

The interview was conducted in the couple's home. I met Anthony briefly. Anna was welcoming, charming and interested in the research project, positioning herself from the outset as a fellow professional. This was the first interview and served as a pilot.

Reworking the narrative of life together after prognosis

Anna emphasised the full and happy life she and Anthony have lived together. The diagnosis of cancer came out of the blue following an x-ray. Anna was tearful as she described receiving the news and their immediate reaction.

> *"Anthony absolutely said, 'How long?' he didn't want soft peddling. We went, we have a little house in [...] France and we were going back there and... (tears)… I suppose we were saying goodbye to the life that we had had together and, er, preparing for the life…as we thought that would be coming, the chemotherapy, and a very brief few months. [...] I …, Anthony's never been afraid to die, it's never worried him, he's totally serene, he's totally calm, he's totally accepting. He just says, 'I've had the most wonderful life, I can't feel sorry for myself.' And he doesn't. I (pause) I just wrote and wrote and wrote, I processed it by writing."*

The terminal prognosis marks a change from the life previously lived, now both celebrated and mourned, and the uncertain territory of a future with illness and loss; the narrative of life together has had to be adjusted. The use of the word "*we"* indicates the couple are facing the illness as a unit, processing the news together. The couple differed in how each received the prognosis; Anthony accepted the news with equanimity while Anna is tearful in recalling this time of heightened emotion.

> *L. Were you able to talk together about what was going on?*
> *A. Yes, absolutely, absolutely everything and we said we'd be totally honest with each other, and we came back, and we talked about death, life, death, all that we'd had….all that we still have…*
> *L. Yes.*
> *A. And when we came back I suppose we knew once we'd come back it's like public property, we had to tell our children, and then everything shifts…. And so….it was almost like a … decompression*

chamber between life as it was, and then we had that week, and then going into something that we didn't really know about, how it would be.

Anna's emotion as she remembers is apparent in her halting speech. The couple used their time alone to support each other, strengthen the couple bond and prepare to face the family and the world. Anna constructs their couple relating as being *totally honest* with each other.

Prioritising the couple relationship

Following the terminal prognosis Anna has devoted herself to Anthony, knowing their time together is limited.

"....When it started, both my parents were still alive and that, I suppose, is in some ways unusual. [...] What I always dreaded was that everything would come together, they would need my care and attention and he would, and that's happened."

"I want, I need to focus on him (Anthony), what he needs, calmly. I can look after him, I can see my mother and that's about it."

Anna's dilemma is in balancing her identity and responsibility as a partner with those as a daughter. Her mother, who was widowed last year, is increasingly frail, lives some distance away and needs family support. Anna's focus on Anthony has precipitated changes in other relationships; she described feeling conflicted over her changing role with her grandchildren.

L. Are you very involved in your grandchildren's lives?
A. No, not nearly as involved as I would like to be.
L. Has that changed since Anthony became ill?
A. Yes, it has a bit, I would have gone and fetched them from school if needs be. And I do miss that because, you know, they're

little for such a short time. That's…. I don't talk about that to Anthony… but I do… I do miss it. Their not calling on us, which is very thoughtful but also…it's sad.

Despite her construction of total honesty, Anna has chosen to protect Anthony from her sadness about this. She recognises the transience of her grandchildren's childhood, another potential loss. Anna's emotion is suggested by her faltering speech.

Anna also used her journal to highlight the conflicting emotions she experiences with her family.

"What I find difficult is to engage emotionally with others' emotional issues: I find it very tiring: whereas before I could give it my all, I can't now and it makes me sad that I can't, irritated (which makes me feel ashamed) that I am being asked to. It feels all the emotional energy is focused on Anthony; nothing over."

This passage indicates how emotionally exhausting this period has been. Anna demonstrates self-reflexivity as she unpacks her reactions to family members sharing their concerns with her and notes a challenge to her previous self-narrative of an engaged, supportive mother. Her priority now is Anthony.

Narrative of time and timeliness

Anna has reworked her self-narrative since Anthony's prognosis. She has learned the importance of living in the present in contrast to worrying about the future.

L. How would you describe that difference, between the time before the "decompression chamber" and the time now?

A. Living in the day, and I've never been very good at that before, always been anxious about the future. And I've absolutely learned to live in this day because that's all we have.

This changed narrative has enabled the couple to optimise their remaining time together. Anna reframes the knowledge of Anthony's limited lifespan as a benefit, allowing them to consciously make this a special time. She draws on a previous narrative of loss as a comparison; the death of a younger friend in an accident some years ago.

"The other thing about that loss, that is wrong, she was 28 and that's nature back to front. Anthony is now 79, he's 12 years older than me and you don't marry someone 12 years older than you without knowing that, as a woman, you're probably going to be the one that's left. Obviously, over time, I'd thought about it and thought this is something likely to happen."

She still feels this unexpected loss acutely. In contrast, she positions losing Anthony as part of the expected life-cycle; he has lived a long, fulfilling life. Anna enlarges on how she has purposefully changed her priorities since Anthony's diagnosis.

A. I'm not nearly so much a Martha, I'm much more a Mary[1] *[...] I used to always be, I've got to do this, I've got to do that, now I think, "Sod it," you know, let it go, "Let's go to a film or go to the theatre, play scrabble or go for a walk on Hampstead Heath together", or whatever it is, you know?*
L. Yes… So it sounds as if it's been quite a special time?
A. Yes… (emotion), it's been amazing….the best time ever, and that's because he's as he is, he's so calm, always makes me laugh, he's so serene.

[1] Jesus visited two sisters; Mary sat at his feet and listened to him, whereas Martha busied herself with preparing a meal. Martha was critical of her sister but Jesus valued Mary's listening to him.

Anna believes her efforts not only enhance life now but will determine her future narrative; enabling her to look back knowing she has done everything she could. She used the journal to comment on time and monitors small changes in Anthony's mental and physical condition.

> *"I think he is looking less substantial than he has done. Maybe his appetite is not as good as was. Hope I'm wrong."*

> *"A's memory very poor today. I am really anxious but interested in how it varies from day to day."*

Anna also reflects on his condition from a more detached, professional perspective. Having outlived the life expectancy predicted at the time of diagnosis 14 months ago, Anthony could be said to be living on *borrowed time*. This lends particular poignancy to Anna's day-by-day vigilance.

> *"It feels like elastic being stretched and stretched – time that is, but also the not-knowing and the ongoing low grade anxiety."*

The *elastic* metaphor works both at the level of the mutability of time and also in the sense that anticipation or anxiety can be experienced as being stretched taut.

Performing and valuing the couple narrative

Anna's couple narrative portrayed a long happy marriage characterised by mutual respect, support and affection.

> *"I've been so lucky; we've had such a lovely life together."*

They have been married for 35 years. As Anthony was well-known and 12 years her senior; this could have shaped the balance in the relationship. Both

partners have led fulfilling lives professionally and personally. They have spent more time together since retirement and still more since Anthony's diagnosis, further enhancing the couple bond.

The couple's narrative template was one of traditional gender roles; Anna taking on more of the caring responsibilities and Anthony dealing with financial and administrative tasks. This pattern, not unusual in couples of this age and culture, apparently suited them both. Since his illness, Anna has undertaken some administrative tasks herself. Anthony's guidance with this is a way of caring for her in a future alone. Anna also emphasised the importance of the emotional support Anthony gives her. In these ways Anthony supports the couple narrative of reciprocal care. She acknowledged that, as a woman, she expects more of herself in a caring role than a man might. Anna brought up the issue of the couple's sexual relationship herself.

> *"It really interests me actually, from the therapeutic point of view, um, that he can't do it any more. But that doesn't mean to say that one can't stroke each other and kiss each other, hug each other, at some level that is actually as good as anything, you know? We did have a very active sex life and… I don't miss it as much as I thought I would*."
>
> *A. We've both learnt, we can make a joke of it, but he knows that I'm not actually saying, "Go on, grr!"*
> *L. And is it always something you've been able to talk about easily?*
> *A. Yes, yes. But also because it's always been a very big part of our marriage. It's been a really nice discovery that we're closer than we've ever been and that's not a part of it.*

Anna positioned herself simultaneously as a woman relating her personal experience and a professional standing back and commenting upon it. The couple have sustained intimacy despite the lack of a full sexual relationship. She also indicates the importance of humour in their couple narrative

Sustaining the couple narrative as illness progresses

Anna constructs the caring that she does now as a continuation of what she has always done for Anthony as a partner rather than as a carer. In her journal she wrote:

> *"I don't think of myself as a "carer" any more than it ever has been. Each of us "cares" for the other. It's still reciprocity."*

The couple have considered the future; Anna acknowledges caring for Anthony will become more challenging and prepares herself to care for him at home. They have organised the practicalities for Anthony's death together and discussed them openly.

> *A. We've done all the practical things. We did them all last year, point, point, point, before the chemotherapy began, so that's out of the way.*
> *L. Did that bring you any kind of ….peace doing that, getting those things done?*
> *A. Yes, it did for him too, that he'd looked after me as well as he could. [...] I know that helped him, having it all done and so when I think now about what's ... I really, really don't want to have anyone else looking after him, if we don't have to, but me. (tears) I'm not sure that he wouldn't like someone …I'm not sure that he feels like that…*
> *L. Doing the physical caring?*
> *A. Yes, yes, he just feels that would be too... I think he might think it easier if a stranger did it in some ways….*
> *L. But you want to be the person?*
> *A. Yes, absolutely, absolutely.*

For both partners planning together increases their sense of agency at a time of uncertainty and sustains their couple narrative. For Anna this reduces her anxiety and Anthony has the satisfaction of helping her to prepare for the

future, one of the ways he preserves his identity within their couple narrative. Anthony may be showing concern for Anna in his hesitation about relying on her for end-of-life care. In contrast, it is important to Anna that she can care for him herself. Both partners work to sustain the relational narrative of reciprocal care.

Anna used her journal to reconsider the couple narrative over the period since Anthony's terminal prognosis.

> *"I do wonder whether these months pass so happily partly do so for myself as this is the first time I think in 35 years that I know Anthony needs me as much as I need him. [...]Then that thought seems rather an impoverished one, a lowering of me really to name it. But I have always thought of him as something of a loner, and complete in himself. It's not that he's overtly dependent, but he wants to know that I'm there."*

Anna self-reflexively re-examines her relational identity; the satisfaction she feels in knowing Anthony needs her is tempered by the shame in experiencing it. This passage indicates a change in her perception of the couple narrative since Anthony's illness; the balance between them has altered. In the final portion of the journal, Anna considers the meaning of being in an enduring loving partnership and what she anticipates missing most.

> *"One of the hardest things of all when I am alone will be accepting / adjusting to no more being the most important thing / loved person in another's life"*

Anna writes from a personal perspective and draws on her professional identity to comment on the value of intimacy for us all.

The private narrative of sadness and loss

Anna recognises that providing care may become more challenging and has been proactive in improving her physical health. She cites the experience of a friend who had not coped well with caring for her partner and contrasts a previous self-narrative of vulnerability with her resolution to survive this period.

> *A. I won't have a breakdown, I've had them in the past, when I was in my twenties, one crashing nervous breakdown; it's not going to happen again. I'm not telling myself that, I know it's not.*
> *L. Yes, you feel quite confident.*
> *A. Yes, I feel grounded and confident that it won't.*
> *L. Yes, yes.*
> *A. And I feel solid mentally within myself.*

Anna mentions her previous history of mental health problems as increasing her resolve to remain strong. Her language emphasises the severity of her breakdown and her determination and confidence that she will remain strong, sustaining her individual narrative. Her repeated statements are a performance of strength, co-constructed by my response.

Anna showed emotion at several points and hints at the depth of sadness she is feeling. She shows how hard it is to let anyone know how much she "*minds*" losing Anthony.

> *L. Do you have any close friends who have been particularly important?*
> *A. Yes, I have a colleague, who is a great friend. [...] But um (pause) I think it's difficult (pause).*
> *L. Difficult to ask for help or difficult for people to understand what's going on….?*
> *A. (Emotion)…No, I don't think so (pause) I suppose it's difficult to (pause) I don't want people to know how much I mind....*
> *L. ...Is there anyone you can talk to?*

A. No, I think that, going back to the writing I did, that's where I processed it and um…. I'd rather just, I do look ahead and think how I'm going to cope with it when the hills get bigger and afterwards, and I think I will cope, I know I'll cope, because actually I'm quite good at being on my own.

Anna's halting speech suggests the difficulty she has in talking about her pain. She pulls back from her emotion to make a positive statement about her ability to cope and to be on her own, reclaiming capability from vulnerability. Given how difficult it had been for her to talk to anybody about losing Anthony it is perhaps surprising that Anna volunteered to participate in a study focusing on the couple relationship at the end of life. She indicates contradictory professional and personal narratives; as a mental health professional Anna was interested in the study but may have underestimated the impact of speaking from a personal perspective.

L. Your sense of not letting people know how much you mind, is this how you've always been or because you feel you need to be particularly strong at the moment?
A. I need to be particularly strong and ...I…it feels too private, this particular future loss….yes, too private.
L. So for other things in the past, if you'd had something you were concerned or worried about, you'd have been more likely to talk it over with someone than you are now?
A. Well, when (her younger friend) died, I had Anthony.

Anna sustains the couple narrative by not replacing Anthony as the person to whom she turns for support yet now, protective of him, this is harder to do. Her performance is of strength and resilience. When Anna first heard Anthony's prognosis, she processed her emotions by writing for herself and this was helpful to her in reworking her self-narrative.

L. Does Anthony know how much you mind?

A. Yes, but I try not to tell him too much because….you know; I just want him to know that I will be fine.
L. How do you gauge how much to talk to him about these things?
A. (pause) I don't want to be a drag on him and a bore…. Um I know he would listen because he's so calm about it and serene, he really is, he really is as he appears to be….
L. Does he worry about what will happen to you afterwards?
A. No, he thinks, he says, "You will be alright, I'm sure". No, he doesn't, I don't think he does worry.

Anna constructs a couple narrative of honesty and transparency about Anthony's prognosis and death; at the same time she wishes to protect him from worry. She sustains both Anthony's narrative of her as someone who will be fine and her self-narrative of strength. Her choice of language here is pertinent; she fears being a *"drag"* or a *"bore"*, terms which disqualify her distress. Anna's cultural template may be to *not make a fuss*, to be *fine* performing composure may be the best way for her to survive the next few months.

The journal: the written self

Anna agreed to keep a journal but found doing so difficult. In contrast to the period following Anthony's diagnosis when she processed her emotional reaction by writing, she felt constrained about putting her thoughts and feelings down in the journal. In our follow-up meeting Anna agreed that this was partly due to the fact that it would be read by someone else. This fits with the interview, in which she acknowledged that her feelings about losing Anthony were too private to be shared.

The *public written self* in the journal differed from the *private written self* in her own writings but provided some insight into Anna's current life and reflections. Day by day Anna continues to monitor Anthony's wellbeing; in terms of his health, energy, memory and appetite. She works tirelessly to support him and

to make each day enjoyable and meaningful, sustaining their couple narrative, her self-narrative and Anthony's narrative of her. Anna reflects on her relationship with Anthony and other family members and begins to consider how her future life will be; self-reflexively commenting on her reactions to daily events and interactions. Anna's voice in the journal was less fluent but addressed similar themes to the interview. In both the most striking feature is her narrative of love for her husband, summed up in the final words of the journal.

> *"A is always smiling, always serene, always the same*. *He is the rock and light of my life."*

Summary

Anna's narrative is of love and anticipated loss. It is an account of a long, happy marriage and a valuing of the couple's life together. She found the interview emotional at times and the journal somewhat inhibiting. Anna draws on a predicted narrative of losing Anthony as an inevitable part of the life-cycle and at the same time the grief she feels is intense and very private. Anna holds multiple positions on what can or cannot be shared with Anthony; the couple narrative of total honesty and the individual narrative of protecting him from her sadness. Both positions help preserve previous couple narratives. The narrative of a close, confiding couple has been an enduring feature of their relationship and protecting Anthony from worry and preserving his narrative of her strength is particularly important now.

Anna emphasised the positive aspects of the time the couple have had together since his diagnosis. In her account she and Anthony work to preserve the previous couple narrative of providing mutual care and support, adapted to the current situation. Some aspects of the couple relational narrative have altered; the balance having changed to accommodate Anthony's increased physical and emotional needs. The couple have

successfully adapted their physical relationship to preserve their narrative of intimacy.

Anna's professional identity was performed in the interview. At several points she adopted a meta-position, commenting on particular aspects of her experience and demonstrating self-reflexivity in her awareness of emotional processes. This worked to preserve her self-narrative as a professional.

Brian

Brian and Beth are a white British couple. At the time of the interview Brian was 63 and Beth 57. They have been married for 40 years; have two adult children and three grandchildren. Brian spent many years in the regular and territorial army. Since leaving the army he has run his own business and more recently worked as a co-ordinator for a company providing care in the community. Beth was diagnosed with ovarian cancer in 2005 and, following a period of remission, has since been diagnosed with multiple secondary tumours.

The interview

The interview was in Brian's home, Beth was not present. Brian was welcoming and appeared eager to tell his story. He was a forthright, articulate interviewee who spontaneously made a number of statements to describe himself. He constructed himself as a self-reliant, capable man who protects and cares for his wife. His positive self-narrative has been partly constructed through his identities as a soldier, entrepreneur, professional carer and husband.

The self-narrative: "This is who I am"

"I'm very strong willed, because of my army training and that. In fact, if I hadn't been in the army I wouldn't have coped half as well as I've done."

"In the past I found it extremely difficult to ask, I normally don't go asking people for help, because if I can't do it meself, then there isn't a problem there."

"I'm her full-time carer now and if it takes me eighteen hours a day to look after her, then I'll give her eighteen hours a day."

"I'm the sort of person that's cut and dried, I don't beat about the bush with people, I'm quite frank and straightforward with them. And I speak the truth, the way I see it, [...] Some people don't like that but that's just the way I am, the way I've been brought up."

It seemed important to Brian that I should understand who he was, a man to be reckoned with. Perhaps at a time of uncertainty and powerlessness it was particularly important to assert his positive masculine identity. As the interview progressed, however, he described how he has begun to change.

"I don't know why I'm actually, why I agreed to go along with this, (the interview) *to be absolutely honest with you. I think my attitude and my way of thinking is changing, because normally, I wouldn't do this sort of thing, [...] I don't normally like people knowing my business. But, I don't know, something's happened over the last couple of month, you know, um, going to this group* (at the hospice)*, seeing Beth, the way she's been reacting, going there, seeing her happy, maybe that's what it is."*

While performing the identity of a self-contained man, Brian is allowing a less privileged voice to emerge.

The *blow-by-blow* narrative

The first part of the interview was taken up by what I have termed a *blow-by-blow* account of the progress of Beth's illness and the couple's interactions with medical services. It appeared important for Brian to tell this story in full and to get the facts straight; he comments on his experience of the illness process.

> *"Oh yeah, it's been a roller-coaster, yeah, it's, it's getting the help and support that Beth needs, it's finding out exactly what's going on, it's just been a mess."*

Brian's account provides a powerful sequential narrative. Most of the participants gave a similar *blow-by-blow* narrative; a compelling illness story within the overall narrative. These stories are discussed in the cross-narrative analysis; I will argue that these narrative accounts are attempts to impose order on series of events over which participants had little control. Brian's *blow-by-blow* account can be found in full in Appendix X as an exemplar.

The couple relationship narrative

Brian constructed the couple relationship as a strong affectionate bond which has survived difficulties in their 40 years together, a narrative of resilience.

> *"Me and Beth, you couldn't get anyone closer than us, [...] we've been through some rubbish in our lives but we've always worked our way through it."*

Brian draws upon a common cultural narrative that surviving hardship can bring a couple closer. The couple met when Beth was very young, married when she was 17 and started a family immediately.

"She's always sort of, in a way, depended on me. You know, anything financial, she gets flustered over it and she'll push it over to me, and I don't mind doing that."

Beth's youth when the relationship commenced and the age difference between them shaped the couple narrative Brian constructs, with him as the wise protector and provider and Beth as dependent upon him. The couple have adopted traditional gender roles in their relationship, perhaps drawing on both family and cultural scripts. In response to a question about claiming disability benefit, Brian emphasises Beth's vulnerability in comparison to his strength.

"If Beth was on her own, sadly she'd have been in her grave by now, with despair. And she'd have given in, given in far, far earlier than what I have."

Brian's account is that without him Beth would not survive; he is her tower of strength. The previous couple narrative is sustained in the context of her illness. Brian describes Beth as following his lead, in her actions and emotions.

B. Beth's always bounced off me, you know, if I say we're going out, she'll come out, if I don't say anything, she won't go out. Beth bounces off me, she draws on my strength.
L. Has that always been the way?
B. It's always been the way, she, if she sees I'm upset over something, she'll get upset over it.

Brian takes responsibility for the emotions within the couple. He constructs Beth's emotional well-being as his duty, his emotions must be managed independently.

B. Beth will get a little bit upset or agitated about something, I feel I have a duty to change it around, to bring something positive out of it.
L. Are you usually able to do that?
B. Most times, yeah. Apart from myself, I just go down the guinea pig shed and kick the wall a couple of times, have a cry, and then come back up again, all smiles, and deal with it that way.
L. In the past, would Beth have been the person, if you were worried about something, or upset, who you could discuss it with?
B. Beth knows, even if I haven't said anything, she can look at me and know if there's something wrong [...] and she does it now, "What's going on, what's up?" And sometimes I don't want to talk to her about it, you know, to say, "This is going on", and "That's going on". Eventually we'll talk about it.

Brian sustains the relational narrative by protecting Beth from upset. He holds back from expressing vulnerability and distress; asking for support does not fit easily with Brian's self-narrative. Beth, however, is sensitive to his feelings, which he values. He counts on her to address his vulnerability without having to name it. Talking to her can be helpful, indicating more reciprocity than is apparent in other parts of his couple narrative.

In describing recent change in their interaction, Brian is reworking the relational narrative, with him prioritising Beth's needs. The tentative aside "*if that's the right thing to say"* is in contrast to his forthright presentation earlier in the interview.

"Yeah, it's helped me to, I'd say, take Beth's interests more at heart, if that's the right thing to say. Beth, if Beth sees me happy [...] in what I'm doing, then she's happy, she'll let me get on and do it. But now, that sort of role is changing, and I've got to adjust to it. I put Beth first, so that role has changed, and my way of thinking has changed, thinking that way as well, so….Yeah, we sort of bounce off each other…"

Brian moves from a description of, "*Beth bounces off me*" to, *"We sort of bounce off each other"*; an indication of reciprocity. He uses the interview to re-evaluate his view and construct a new narrative of the couple relationship. When asked if there was anything further he wanted to discuss, Brian, after some hesitation, took the opportunity to discuss difficulties in the couple's sexual relationship.

> *B. Urm (pause), I think, I think, one thing that has crept up quite recently, is being intimate between us. You know, we've always been a very loving couple but, quite sadly, over the last couple of month, that's gone on the back burner. Because Beth, now that we are talking about it, she finds it very uncomfortable. [...]*
> *L. Have you talked about it?*
> *B. And I say, "Whenever we do it and it gets painful, just tell me and I'll stop".*
> *L. Yeah, yeah.*
> *B. And we just leave it at that, you know, there's not a great deal else I can do about it. She gets extremely upset about it, over that, um, but I just don't know any other way around it, at the moment.*
> *L. No. Are you still able to be loving with each other in other ways?*
> *B. Yes we still have us cuddles and we still have us kisses. You know, we're always walking around holding hands and that. And that's the way it will always be.*
> *L. Yeah, yeah.*
> *B. That's how we've always been, nothing will change. I get upset, because, we're not intimate, but it's not the end of the world.*
> *L. No.*
> *B. It's upsetting that it happens but then I have to take Beth's condition into consideration, be considerate about it.*

The importance of the physical relationship in the couple narrative is apparent, as is Brian's sadness at the loss, although here he privileges consideration for Beth. In constructing his self-account Brian is talking himself into a position of

acceptance, although the loss of a full sexual relationship may challenge his masculine identity. The couple narrative of intimacy has been preserved in the altered sexual relationship.

The couple narrative of illness

Brian constructs Beth's illness as something the couple have faced as a unit from the outset. This is underlined by the extensive use of the pronoun *we* throughout the interview.

> *"She said, 'Look, I got a lump here on me breast', and I said, 'Well, we'll keep an eye on it over couple of days, [...] and if it gets sore, then we'll whip you up to the doctor's like', and, unfortunately, that's what we had to do."*

> *"So I strongly said to her, 'We can't keep going along with our doctor's decision, we'll have a second opinion.'"*

Brian's account demonstrates a couple narrative of resilience: strength and closeness through adversity. They have approached Beth's illness in a similar way. Brian positions himself as Beth's champion, taking the initiative for ensuring her symptoms are investigated. Brian's relational narrative as Beth's strong, wise protector, is of particular benefit to both partners now. Beth is supported in accessing help and Brian has the satisfaction of knowing his actions have been helpful to her. Brian also emphasises how he shares in the trauma of metastatic cancer.

> *"But then in a short space of time we went from category 1 to category 3. So we went to hospital and they removed her breast, [...] that was a very traumatic time for both of us."*

The rapid progression of the disease has disrupted the couple's expected future narrative. In the earlier stages of the illness the couple drew on their

previous couple narrative of resilience to overcome difficulties together. As the disease progresses it has become more difficult for them to discuss the implications; they have not yet established a template for end-of-life talk.

The *professional carer* identity

Brian utilises his self-narrative as a *professional carer* to inform his current experience. He demonstrates pride in his work as a social-care professional.

> *"I worked my way up to team leader, you know. And I really enjoyed the work because I could see that people were enjoying my company and the help I was giving them."*

The professional skills Brian developed have been drawn upon in his care of Beth, shown here both in actions taken and language used. By extensive use of direct speech Brian brings the account alive, emphasising his active management of Beth's care, a performance of his competency while positioning her as a passive recipient.

> *"I set up a chart for her, when she was going through the stages with the morphine and steroids, just so she didn't get confused. I said, 'Put a tick by the side of it. So that not only refreshes your memory, it jogs me to know that you've taken your medication, cos I don't want to interfere, to be in your face all the time, Have you taken your medication, you know'".*

While the established pattern in the couple narrative is for Brian to take the initiative, he also shows sensitivity, monitoring his behaviour to avoid taking over. The language used below is more reminiscent of professional talk than a couple relationship.

> *"What I try to do with her, I deliberately leave things to prompt her to do something, to keep her active. If I didn't do that, if I started*

taking over, she'd just sit in the chair all day, and that's not only unfair on me, most importantly, it's unfair on her, because it's not motivating her. And I need to keep her focused and motivated."

Brian demonstrates concern for Beth's wellbeing by holding back to help her. What is missing from the account is any sense of Beth's voice or agency in all this. Does she appreciate his efforts? Does she welcome being *motivated*? Brian highlights the difference between the personal and professional.

"But when you're working in it (domiciliary care) *as a job, you go in, you give the client what they want, and you look after them in the most dignified way you can, and then you walk out of the door and leave it behind. But when you see it in front of you 24 / 7, it's a totally different kettle of fish. When you see your partner, that you've been together with for 40 odd years, slowly deteriorating away, and there's not a thing you can do about it, and it's not cos of anything that Beth's done wrong in her life, she's never smoked in her life, she's never drunk in her life"*

Brian indicates the impossibility of distancing himself from Beth's suffering. His sense of powerlessness prompts him to be a motivated and motivating carer; he cannot cure her but works tirelessly to maintain her health. Brian has reached the limits of his professional identity and it remains important to be effective where he can. His strong sense of injustice is apparent.

Spoken and unspoken narratives

In the earlier stages the couple faced Beth's illness together. As the disease has progressed, communication has become more difficult and, until recently, the couple avoided discussion which acknowledged that Beth was dying. Brian's narrative indicated he took responsibility for initiating discussion but avoided these sensitive areas to shield Beth from upset; this may have silenced Beth.

The following extracts illustrate Brian adopting multiple positions: planning a holiday and researching options for Beth's funeral. Holiday plans are made together, even as the future is uncertain, while Brian protects Beth from the knowledge that he is thinking about her death.

L. Do you talk about the future at all, what it might hold?
B. We have talked… about holidays, about certain things that are coming up in the future. When I first found out she got secondary liver cancer, my first reaction was, sadly behind Beth's back, I was on the internet, looking at funeral plans, because, a) I didn't know who to talk to, I didn't know where to turn, it's a subject I didn't want to talk to Beth about.
L. Mm.
B. I felt I needed to put something in place, because nobody knows when it's going to happen, even now, we don't know when it's going to happen, how long Beth has got.
L. No, no.
B. Er, and I felt the only way I could start helping her was by finding out about funeral plans.
L, Mm.
B. I haven't done it, I stopped it, because, a) I'm getting myself worked up about it, because I don't know what the future holds for us, or when it's going to happen. We've booked a holiday, um, in September, we're going up to the Norfolk Broads, I've hired a cruiser for a week, so we're going to cruise round the broads.

On receiving the devastating news of secondary liver cancer, Brian's inclination was to take action, addressing the helplessness engendered by the terminal prognosis. This supports his relational narrative as the man who solves problems, protects and takes care of his wife. Brian was unable to talk to Beth or anyone else about her death, his self-narrative of self-sufficiency leaving him isolated. Seeking information about funeral plans, rather than

bringing peace or certainty, increased Brian's anxiety and he turns instead to positive short term plans.

Brian has had to adopt multiple positions and to draw on contradictory discourses; taking care of Beth means both taking responsibility for practical arrangements for her death and maximising her comfort and pleasure now. The time frame is uncertain and Brian wishes to make the most of their remaining couple life. Making plans together for a holiday sustains the couple narrative and sustains hope for the short term future.

> *L. So, you've planned your holiday and you're looking forward to that, um, but the uncertainty may be about the longer term future, um, how easy or difficult is that for you?*
> *B. Personally, for myself, I can't talk to Beth about funeral arrangements, I'd love to say to her, you know, "Duck, we got this discussion to talk about, when the inevitable happens, what do you want, what do you want me to arrange? Do you want to stay here? [...] Or do you want to go down to where your family's from? Go down to the crematorium down there?" I just haven't got the heart, to talk to her about that.*

Brian has rehearsed conversations about funerals but it has been too painful to speak out; he sustains the previous couple narrative by his protective silence.

The following discussion instigated by Beth challenged the couple's communication pattern. As Beth's disease progresses, conversations previously unthinkable may now become possible or necessary. The silence has now been broken, the following conversation having been instigated by Beth herself. It is reproduced in full to elucidate the work being done by the narrative.

> *L. Have you had any nursing help at home?*

B. Not at the moment, at the moment I want to take it as far as I can myself.

L. Did you and Beth talk about that?

B. We have had difficulties talking about this. But on Sunday, I thought, "I'll spend a couple of hours with her watching television" and she said, er, "If"- just out of the blue- "If the chemotherapy, if this next lot of chemotherapy doesn't work, I'm not going to take any more medication. What do you think?" And, er, my jaw just dropped open… And I sit for a little while, and I think about it…you know. At first I didn't know how to react to it, because that's… something totally out of character for Beth to say.

L. Yeah, yeah.

B. And I said, "What did you say?" and she said, "Well I, do you think I should give up this medication?" And I said, "Well, I can't answer that one for you, duck…, I…Whatever decision you make, you have to make it yourself. ***But*** *whatever decision you make, I'll support you one hundred per cent. I can't make the decision for you; I can't tell you, "Yes, stop it or no…. ", whatever, there's only you that can do it, there's only you that can make that decision, I'll support you whatever decision you make. I'm sad that you've got to make that decision but, but, looking at it on reality, if the first lot of chemotherapy hasn't touched this cancer at all, then to go through this course of second medication, and that doesn't help, then maybe you are making the right decision. Because, if you're being spaced out and you're having really rough and crap days taking medication, and your not having the quality of life that you should be having, and you feel now that you are having a better time until 'him upstairs' sort of says his few words to you"...*

L. Yes.

B. "And you can have a better quality of life off the medication and you're going to be able to do more, then fine, I can cope with that".

L. Mm.

B. She said, "I've been talking to these people I've been meeting up at the hospice, and they've made that decision, and they say

they're having a wonderful time, being off the medication, you know, and you're having a far better quality of doing things…" And so I realised, where this had come from.
L. OK, yeah.
B. Because she's heard other people at the hospice. She hasn't been influenced by them, but she sees them doing more, by not being on the medication, because if the medication is not helping, what's the point of taking it in the first place?
L. It's opened up the conversation?
B. Yes, it has. So, I said, "If that's the decision that you make, you make it, and I'll support you on it."
L. Mm.
B. "It's all I can do, I can't force you to take your medication, I can take you to water but I can't force you to drink it."
L. No, no.
B. "I don't want to influence you in any way, you've got to be the person that makes the decision, I'll be the person in the background, backing you."

The work of the narrative is apparent in the reported conversation and reinforced in the process of the interview; it marks a significant shift in the couple's narrative of Beth's terminal illness. Beth has been considering her options regarding stopping chemotherapy and is speaking of it for the first time, asking for support. Beth reaching such an important decision herself and opening the conversation about it represent a departure from the couple's previous narrative. Brian's account indicates how he is working to understand and accommodate Beth's position. He uses the interview to process and develop his change of position. He takes hold of the idea of supporting Beth in her decision; using direct speech, he repeats the message many times, in several different ways. His talk is reinforcing a relational narrative which may not have been easy for him to adopt, accepting a communication pattern in which Beth takes the lead. At the same time Brian emphasises the importance of his supporting role.

The conversation is critical in acknowledging that active treatment is no longer the best option for Beth, quality of life is now the priority. Underlying this is the acknowledgement that she is dying. This conversation marks a shift in the couple narrative. Facilitated by the discussions in their respective hospice groups the couple have adopted a new relationship to Beth's illness.

Brian brought up the next, very sensitive, subject right at the end of the interview.

> *B. The other thing is, I mean, I have, not that I've told Beth, I've thought about going with her, when she goes.*
> *L. Have you?*
> *B. I don't know if that's the right thing to think about or not, I don't know. I don't know what my future holds.*
> *L. To be on your own?*
> *B. To be on me own. I mean I've always coped well, I've been in the army on me own, um, I don't know.*
> *L. Do you think there would be a point when you would want to discuss that with her or discuss it with anybody else?*
> *B. I don't think Beth needs to know that.*
> *L. Mm, mm.*
> *B. She's, I imagine if she thought I was thinking along that line, then she'd get extremely upset about it, because she'd think, "That's totally out of character with you."*

Over their long marriage an important part of Brian's identity has been as Beth's partner and protector, intensified since her illness. In losing Beth he risks not only losing their shared couple identity but part of himself. It is notable that, in the context of an interview in which Brian made many references to how much Beth depended on him, this is the only explicit example of how much he needs her. Brian had not discussed these thoughts with anyone else and I encouraged him to do so. He was not depressed and was not describing intention; I understood it as an expression of how difficult it was to contemplate life without Beth.

Summary

In Brian's narrative he performs the identity of the strong, protective man continuing to take care of Beth throughout her terminal illness. The narrative of the couple relationship is one of an enduring affectionate bond, overcoming adversity and becoming closer as a result. Over their long marriage the couple have developed reciprocal roles; in Brian's account he has assumed the identity of the wise, competent partner upon whom Beth depends. Although Brian privileges the narrative of the protective man, there is also some reciprocity; Beth follows a traditional gendered narrative, sensitive to Brian's emotional needs and doing what she can to support him. These positions support the couple narrative of resilience.

Brian emphasises Beth's dependence on him but losing her is a threat to his identity and he is unsure how he will live without her. The protective silence regarding her terminal prognosis, now breached by Beth, may have denied both partners the opportunity of mutual support at a time when they most need it. In facing the challenges of Beth's illness Brian draws upon previous narratives of himself as a self-reliant, resilient man and a competent professional carer. Although he initially portrays himself as somewhat fixed in his position, there are indications that Brian is now adapting to accommodate the change in Beth's own changing perspective on her illness.

Brian reflected upon how agreeing to be interviewed was out of character for him; speaking out would have previously represented a challenge to his narrative of self-sufficiency. He attributed this change to the couple attending the hospice support groups. Brian used the interview to unburden himself, to express and process difficult thoughts and emotions not previously shared. He drew on various narrative identities; the wise, protective partner, the experienced carer, the forthright, self-reliant coper and the less privileged voice of the uncertain, vulnerable man contemplating the loss of his partner. This may have been possible because of the context of a one to one interview

with an older, female researcher and perhaps because he knew we would not meet again.

The work of Brian's narrative is to confirm him in his positive identities and enable him to *hold his own* yet also to voice his vulnerability. It helped him to order and make sense of a chaotic period; reclaiming some agency over uncertainty and powerlessness. The narrative identifies and enacts a shift in perspective which takes more account of Beth's changing needs and allows Brian other options.

Colin

Colin and Carol are a white British couple in their mid sixties. They married in their early twenties and have three children, all married with children of their own. The couple continue to be active in their local community. Carol was diagnosed with cancer two years before the interview. A year of chemotherapy was followed by a terminal prognosis. Both have retired since Carol became ill. In the past Colin has been an entrepreneur and business consultant.

To aid the analytical process I wrote a letter to Colin's narrative (Appendix XIV) This letter helped me to identify how the narrative drew in the listener (or reader) by its lively and amusing presentation and how much thought Colin had put into his narrative. It clarified the identities performed in both the interview and journal and highlighted the contrast between them.

The Interview

The interview was conducted in the couple's home. Carol and a friend were chatting in an adjoining room so there was not complete privacy. Although Colin emphasised that he and Carol had always been completely open with

each other, I was aware that it could influence the interview and possibly deter Colin from more sensitive disclosures. He was friendly, welcoming and determinedly up-beat throughout our conversation, frequently using humour when describing his life and relationships.

Performing positivity

Colin describes being told of Carol's diagnosis.

> *"It largely came out of the blue…it was a shock. We had 'a cunning plan'[2] that we were going to grow old together, and sort of shuffle off into the sunset arm in arm."*

Colin uses humour even as he describes receiving the devastating news of the cancer which will disrupt their imagined future together, setting the tone for the interview. He draws upon a couple narrative of up-beat resilience when describing the couple's reaction to the terminal prognosis one year later.

> *C. We've always had a sort of open relationship anyway, so we sat down and talked about it, [...] and then we got the terminal prognosis…, and, basically, we've been partying ever since! (laughter) I think it's a fair way to put it!*
> *L. So, that's what you did, you thought, "We've got this amount of time so we're going to…?"*
> *C. We made the most of what time we've got left.*

Colin's determinedly positive description of what must been a difficult transition is a performance of his identity as a cheerful and resilient man. He draws on a couple narrative which prioritises both transparency and making the most of life. He continued to describe their life since Carol's terminal

[2] *"A cunning plan"* references the 1980s television comedy programme, "Blackadder".

prognosis; they have always been sociable and are resolved to live life to the full.

> *"So we've waded through Carol's bucket list, we've travelled here, there and everywhere."*

Colin takes obvious pride in how they are negotiating this stage of their life and is keen to tell the story of all they have done together, using humour whenever possible. In contrast to this portrayal, Colin described a recent emergency admission to hospital himself for gastric surgery.

> *L. Are you the sort of person that if you do feel you need to talk to someone, then you can?*
> *C. ...I can, I mean I've seen a couple of the counsellors, when I came out of hospital having had my stomach done, I really was in a bad state, I really was, and I saw one of the counsellors for two or three weeks, and it sorted itself out. I got a bee in my bonnet, I promised I'd take Carol to see the daffodils at Cambridge, and with the operation I couldn't do it, it really upset me (tears). I don't like breaking a promise.*

Colin's reaction to being unable to fulfil a promise gives some indication of the high standard he sets himself in caring for Carol, his relational narrative as a devoted partner doing everything possible was challenged by his own illness. This was distressing at the time and in retrospect. In contrast, Colin is aware that other people are concerned that he doesn't show his feelings. His response is pragmatic.

> *C. I sometimes get a vague feeling that some of my friends think I'm not doing it quite right, although there is not a right way to do it….*
> *L. What do you mean by that?*

C. Well they think I should sort of display more emotion, or… When Carol goes, then I suspect I'm going to fall apart at the seams, but at the moment, that doesn't benefit anyone.

Colin positions expressing emotion as a choice; he need not do what others expect of him. Thus he protects both himself and Carol and works to sustain his self-narrative of pragmatism and resilience. He acknowledges the sadness he may feel and express differently in the future. Colin uses the reaction of others as a counterpoint to personal and family beliefs.

"Sometimes we'll go out and we'll be talking to people and you can see people looking a bit askance. If you're out at dinner somewhere and you're talking about these topics, and joking and laughing about it and you can see people thinking, 'Should they be doing that?' Why not? You can't change it so you may as well get a laugh out of it."

Colin relates this with pride; he is aware the family's beliefs about death may be at odds with prevailing social mores but relishes the difference, continuing his performance of positivity.

Drawing on past narratives

In caring for Carol today, Colin draws on his experiences as a *juvenile carer* for his mother, an individual and relational narrative. He is aware of the changing social discourse on this issue.

C. When I was nine, my mother caught polio in one of the last big epidemics before the vaccine started kicking in, and she wound up quadriplegic. So, I suppose nowadays I'd be counted as a juvenile carer. Mum and Dad were fantastic, Dad held down a senior management job, and we got some help, but not a huge amount. So I grew up, used to dealing with people who are dependant.

L. Do you remember what that was like?
C. It was the way it was, it didn't feel unnatural. I was a new man before they were invented, I could cook, and then I trained as a chef, I can wash, I can iron, I can do all the housework, so dealing with it in some ways was just coming home, it wasn't strange.

Colin turns what could have been a narrative of disadvantage to advantage; recounting his proficiency with satisfaction. The privileged narrative emphasises fortitude rather than difficulty. Colin's acceptance of Carol's illness and the changes in their lives echoes his narrative of his mother's illness and his role in her care. He developed competence early and his performance of capability is invoked in his current self-narrative.

"It's not difficult, we're comfortable with each other, with each others bodies, and again partly, growing up with Mum, she had to be helped to do things, to do everything. So I don't have any trouble touching bodies."

Colin positions himself as a professional, which he posits as offering some helpful distance.

L. So, the practical side of caring came quite naturally to you?
C. I'm, I'm, a combination of things, I suspect that I'm detached in the way that health professionals are detached, it's not uncomfortable or difficult or awkward, what needs doing just gets done. It's perverse, but in some ways I'm better suited to this and luckier than most people, because it's familiar.
L. What about the emotional side of it?
C. It came out, one of the things that came out from Mum and Dad, not just a practical model, but a model of how to live, and how the relationships work, and I'm, I would argue that I'm self-disciplined and self-controlled, and I cope, I'm accepting, what I can't change I'll just accept. But you could argue I'm just totally repressed I suppose!

Colin self-reflexively recognises and values his family template, he does not directly address the question about emotion. He describes his personal characteristics in language reminiscent of his management training but then apparently notices this and switches to the somewhat self-depreciating humour used throughout the interview.

Performing masculinity

Colin does not view doing tasks traditionally viewed as *women's work* as demeaning, he takes pride in them. However, for the first time in his life he has relinquished his role as a breadwinner and given up other positions in the community which may have brought him respect and confidence as a man. This informed Colin's self-presentation as an effective, successful man in the interview.

> *"When I was on (*management training*), we did a lot of psychometrics, and I came out the same on all of them; I'm extrovert, tend to be at the extreme of whatever continuum you're looking at. So I have a high tolerance of stress, I have a high tolerance of uncertainty, I'm resourceful, I'm imaginative, all of which is great you know!"*

This performance of proficiency directly followed the description of his vulnerability after surgery, re-establishing strength. This statement is tempered by irony at the end. Throughout the interview Colin makes frequent comparisons between his own reactions and those of other men in similar situations.

> *"You know, because of my background I am who and what I am, I think it's given me a huge edge, I know the hospice were saying they had four men, whose wives had died or were dying, who*

couldn't cook, so they arranged for cookery courses. I've got none of that. In purely practical terms, I can cope comfortably."

This comparison positions Colin as both competent and fortunate in being able to draw on previous self-narratives and skills. Colin speaks candidly about his changing relationship with his son.

C. There's a slight conflict…. you probably get anyway as you get older and you get to retirement, [...] It's very easy to become a scruffy old nonentity. Yeah, we go out with the kids and certainly I'm not the one that's in charge.
L. Yeah.
C. You go out with my eldest son, a 45 year old alpha male, and you can see, at 45 that's what I was.
L. Is that difficult?
C. Sometimes it's uncomfortable, sometimes it's just amusing. You take a look at it with a wry grin and think, "Well, it would have been me but it's not any longer", you know.

Colin demonstrates self-reflexivity and humour in his understanding and acceptance of the evolving relationship, minimising any difficulty. Reviewing his past self-narrative, he acknowledges the loss of his role in the family but positions it as part of the life-cycle. The stark contrast between a *scruffy old nonentity* and *alpha male* highlights his changing options as man. In Colin's journal he speaks with admiration of his grandfathers, both of whom fought in WW1. He describes his maternal grandfather as his hero, citing his cheerfulness and kindness despite adversity, commenting:

"It's sad that whatever I do I will never be half the man my dad and my granddad were."

Although Colin cites these templates of masculinity as difficult to live up to, he certainly tries to make them his own.

The couple relationship narrative (interview and journal)

Colin brought a communication pattern of transparency from his family of origin to the couple narrative and the couple have drawn on this in dealing with Carol's illness.

> *C. ...But we wanted to, we said from the outset, we want to know, we want to know everything there is to know.*
> *L. Yes. And that knowing, how is it helpful?*
> *C. I feel aware, there's no nasty surprises, you know pretty well what's going to happen, so you can prepare to a degree.*

Following the family and couple template, being prepared becomes a survival strategy. Colin again positions them in relation to other couples in describing end-of-life planning.

> *"It does make it easier because you know, I know exactly what Carol wants, and we talk about it sometimes in the car; something will just spark a conversation. From the outset, we said to the various clinicians, 'We want to be told everything, both of us.' I need to know, it's much easier if you know what's going to happen, what to expect."*

The couple have approached Carol's terminal illness jointly and pragmatically, seeking and processing information together and sustaining a couple narrative of resilience. They have accepted that her condition will deteriorate and that she will die, the only uncertainty being the timing and the detail. Missing from Colin's narrative in the interview is expression of the emotional impact of this knowledge. Below Colin reflects on Carol's illness.

> *"Longer term, if you've been married a long time, you must, if you're sensible, know that one of you is likely to decline, and one of you is likely to go first. All that's happened is the timing has gone, you know, we should have had another 15 or 20 years together."*

Colin constructs the death of one partner as part of the expected couple narrative but this narrative has been interrupted by the timing. While acknowledging that they *"should have"* had more time together, perhaps hinting at the injustice of losing her, he expresses little sadness or anger in the interview. This may have been informed by Carol's proximity in the next room or a wish to protect his identity as a resilient, positive man.

Colin and Carol have been together for 46 years; their entire adult lives. The couple narrative Colin presented was one of love, mutuality and respect. They have faced life as a couple and are facing Carol's illness in the same way.

> *"I'm her husband, her partner. It was the deal. The deal was, you get older, you know something like this is going to happen. And one of you, possibly permanently, possibly short term, will have periods of ill health."*

Colin rejected the term *carer*; framing his current role with Carol as a natural and expected part of a couple relationship, supporting the couple narrative of reciprocal care.

In the journal Colin recaptured memories of the romance of his early life with Carol, triggered by a song on the radio.

> *"....driving through the autumn sunshine to the finals of a beauty contest that Carol was in. We were happy together and at the start of a love-affair that has lasted 46 years."*

In describing how the couple have made the most of the time left together, Colin reinforces and sustains the couple narrative.

> *"While the last two years have been difficult in many ways and we know what the ending will be, it has been one of the happiest times of our life. We are even closer than we have been in the past and*

have been living our lives to the fullest. Many people have commented on how happy we seem; sometimes they seem unsettled by this."

Colin again uses other's views as a counterpoint to his own, emphasising how special their relationship is and how successful they have been in making the most of their last years together.

Revaluing the couple narrative

Prior to Carol's diagnosis, the couple were making a film of their family life and Carol is now working on a written document with photographs. Colin describes them as often looking back on their life together. This project, in the context of limited time left together, has prompted further reflections, mainly positive, and a desire to preserve stories to pass on to the next generation. The work the couple have put into making the last year so special could also be interpreted as a way of creating and preserving a positive narrative to be drawn upon in the future. Colin celebrates the positive and is pragmatic about the negative.

"We're lucky we have a life that is largely comprised of happy memories, and the unhappy ones were never so traumatic or so appalling that they wrecked our lives. [...]But for the most part, yeah, we've had a wonderful life. We both had good childhoods, with good supportive families, back through the generations. We knew our grandparents, and our children grew up very close to their grandparents, as we've been close to our grandchildren. And I think, for children, it's important to see yourself as part of something bigger."

Colin draws on a narrative of family life over generations. He cites the importance for grandchildren but now, with the prospect of losing Carol, takes comfort himself from the idea of being part of a family story which goes back

before his birth and will continue for generations to come. Looking back on the period since Carol became ill, Colin acknowledges a change in his life view.

> *L. Do you think you have changed as a person since your wife became ill?*
> *C. Possibly less optimistic, there's not a lot to be optimistic about... I suspect so, but I don't quite know how.*
> *L. Mm.*
> *C. I suppose, a bit more accepting, you know, I can't change it, so I've just got to live with it…. But on the other…, it's been… humbling, the way people have gone out of their way to help.*

Colin acknowledges the negative, then moves to pragmatism and to comment on the kindness of the community and how fortunate they are. This may partly be a function of his performance of the cheerful, resilient man within the interview. The journal reflects another narrative: the sad vulnerable man who fears for his future alone.

Narrative of love and loss (journal)

Colin describes using his daily time alone walking the dog as a time of reflection or: "*meditation on the move"*.

> *"I keep getting visions of how life will be without Carol; it's a bleak, hostile foreign land. I fell in love with Carol when we were both nineteen and stayed that way for 46 going on 47 years. Everyday I've had the certainty that I love and am loved in return. I have never been truly alone throughout the whole of my adult life, it's a terrifying prospect. I know that my family love me but it's not the same."*

In contrast to the performance of positivity in the interview, Colin considers the bleaker aspects of his imagined future. He contrasts the couple narrative of enduring mutual love with a possibly bleak future narrative.

> *"Trying to image what it will be like and how I will cope defies imagination. [...] Without Carol I will be diminished almost to the point of being valueless. I see it as being like trying to image life without one of your senses, or with a limb amputated. You may have a vague sense of what is involved and the pain, how you will cope, but deep down I know the reality will be worse, much worse. Looking after Carol while she needs caring is well within my compass, coping on my own once she has died I fear will be beyond me."*

In losing Carol, Colin is losing his relationship and his relational identity. His worth and his identity are determined by their relationship. In contrast to the self-narrative of confidence and strength, he writes in the less privileged voice of self-doubt. The powerful metaphor of an amputated limb underlines his sense of loss. In acknowledging his fear and vulnerability so directly, Colin is using the journal to begin to process them and to mourn.

> *"I know that next year will be the worst in my whole life and I dread the thought of what is to come. Truly this will be the winter of my soul. It will be a time of incredible pain, sorrow, loss, anxiety, grieving etc but for all this I think I will fundamentally be happy. I am by nature a happy soul and it is my belief that happiness springs from within. I choose whether I will be happy every day. Events and people's actions influence this but the choice to be happy is mine and mine alone."*

Colin's written self is a consciously constructed self: the language used suggests the thought Colin has put into this journal entry. Colin mitigates his darker reflections by introducing a more optimistic perspective of his future alone. Drawing upon previous self-narratives of resilience and cheerfulness

he frames happiness as a choice. Constructing himself as having agency lessens Colin's sense of vulnerability.

The narrative of time (journal)

Over the three week period during which Colin writes his journal, he notes a gradual deterioration in Carol's health.

> *"Carol had a terrible night woke up at about 2 am with intense pain in her back. [...]This is the second incident like this within a few days; I fear that this is a sign of what is to come. I hate the feeling of helplessness."*

Colin observes the progression of the disease and his own reaction to it. He is acknowledging that the pragmatic resilience narrative which has served the couple well until now is not enough for the future.

> *"To date whenever her condition has deteriorated I have dealt with whatever problems have arisen and focused on the next distraction we have planned. This is less and less viable as a strategy, one by one the things that underpin the fabric and structure of my life are weakening and disappearing."*

Optimising time together has given Colin a positive focus. As Carol becomes increasingly unwell, previous self and couple narratives are challenged. His self-narrative of the able, optimistic man is harder to sustain and his relational narrative as a husband who brings joy to his wife is challenged. The couple relationship narrative of enjoying life and facing difficulty together is now time-limited.

> *"It must be strange for Carol to know that you are doing things for the last time [...] I find it difficult because I know that I will be able to*

do these things again, but on my own it will not be the same or worth doing."

Colin's awareness that Carol may be doing something for the last time lends poignancy to everyday activities and highlights the difference in their future narratives. Without her, previously enjoyable pursuits may become meaningless.

Temporality can become distorted at the end of life, both for the dying and their family; time can appear to be extended or compressed. Carol and Colin were given a 6 month timeframe at the time of the terminal prognosis: this was 19 months ago.

"While walking I was suddenly struck by an overpowering sense of time passing quickly and that time is running out. There is so much to do and I will be so lost without Carol."

"It gets a bit surreal after a while, you know everything is going to end soon, you know pretty much what is going to happen and how you hope you will deal with it, but the event keeps being put back. It creates a terrible sensation of anticipation, expecting the worse and then a slow reprieve and sense of anticlimax."

In the earlier stages of Carol's illness, the couple narrative continued on a familiar trajectory, albeit curtailed. Plans could still be made and carried out and the short term future had hope and predictability. The limited time-frame even brought additional pleasure and meaning to this period. In contrast, Colin now experiences temporality as disrupted and unpredictable. The uncertainty of the timeframe combined with the certain knowledge of Carol's death provokes anxiety. In the following journal excerpt, Colin reports a friend commenting on how well Carol looked.

"One of them said, (to Carol) 'I think you will go on and on, you have years left to go'. At this I thought, 'Dear God no, I can't keep

this up for much longer, there has to be an end to it soon.' Now I feel guilty for being disloyal. I know how much Carol is beginning to suffer and how much less she can do, if she goes on much longer she will become a total basket case and neither of us want that!"

Colin notes his own horrified reaction to this, bringing to awareness the knowledge that he does not want the situation to continue indefinitely, for Carol's sake and for his own. The phrase *keep this up* indicates the toll the last months have taken on Colin. This is followed by guilt at having these thoughts and a decision not to share them with Carol. Colin finds a familiar refuge in dark humour.

Constructing a future narrative (interview and journal)

Colin has considered many of the practical aspects of Carol's death. In addition to planning a funeral and burial, he has prepared a plan to help him immediately after her death.

"I'm working through what's got to be done, so I've got a spreadsheet with all the important phone numbers, I don't want to be trying to look up registrars of births and deaths with tears in my eyes, I just want to, there it is. Thinking in practical terms about what's got to be done".

Colin's *thinking in practical terms*, having a spreadsheet and strategy, privileges the performance of competency rather than vulnerability. For the medium and long term future, Colin has done less planning. For the first time in the interview he loses some of his fluency and appears uncertain and perhaps sad. However, humour again comes to his rescue.

L. Do you think about the future very much, just now?
C. …Yes, yeah… I… It's a bit hit and miss, because I've got to get through the initial period, I've got to sell the house…

L. ….Mm.
C. After that, it's all a bit grey and uncertain…
L. Do you talk to the rest of the family about that?
C. Well, they know I've got to sell the house, but, beyond that, you don't know, you don't know. I mean, my father…. he wound up, he found himself a lady friend, he was very happy the last… But, I don't know, something like that may happen, I might go the other way, I don't know.
L. Mm.
C. I, I joke with them that I just want to live long enough to be a burden! They tell me I'm an embarrassment already, so I'm well on the way!

Colin has given the future some consideration and uses his father as a positive model for future possibilities. At the moment it could seem disloyal or inappropriate to plan for more than the short term future. In Colin's journal he further considers his future and two themes emerge. In the first he contemplates loss and absence, a void in which life has lost all meaning. At other times he considers what possibilities may be open to him.

"Meeting like this is fun, but I do wonder what will happen after Carol goes. Currently I go to things like this as part of a two-headed symbiotic creature "ColinandCarol". Will I still be welcome as just Colin and will I want to go anyway? It might just be easier to hide away for a while."

Colin shows the strength of the couple narrative. He describes a gathering with friends and compares his current social identity as part of a couple with an imagined future alone. He is unsure of his future value alone, how he will construct himself a single man and what his future narrative will be.

"Looking at what comes next, once Carol has gone and her estate is sorted, I can foresee a life where there is no structure, no sense

of belonging and no purpose. Losing Carol will diminish me to the point where I may become valueless."

Colin fears the loss of his relational identity. He questions whether the traditions, rituals and meanings around which he has built his personal and couple narrative can survive. His identity is threatened by losing the person with whom he constructed himself as a man, a husband and a father over so many years.

At other points in the journal Colin writes more optimistically of future plans. He considers the pros and cons of a future relationship in the light of others' experiences.

"In purely practical terms I am completely self-sufficient but emotionally I think I will be totally lost. The temptation is that I will get into a new relationship, any relationship, just so that I am no longer alone."

Colin demonstrates self-awareness in recognising his need for companionship and the potential danger of this. Solitude is unknown territory for him.

"Potentially I could have another 20 or so years left, living that alone or vicariously through my children and grandchildren is not a prospect I relish. I know that it is possible to form new, worthwhile relationships."

He is equally clear-sighted about his future relationship with his family. He cites his father, for whom he had great respect, as a positive example of another relationship becoming a second chance at happiness.

The journal

Colin opted to keep a journal by email and sent it to me daily for three weeks. The tone of the journal is very different from that of the interview. In the interview Colin was up-beat and amusing and minimised any emotional difficulties in his current situation, perhaps enacting both the man as he would like to be known and the man he believed I would like to interview. In contrast, in the journal he reflected on his sadness and fears as well as more positive aspects of his life. Colin started the journal at my suggestion but he also wrote for himself. He used the journal to give space to other, less privileged voices and narratives in his repertoire.

Summary

Colin approached both the interview and journal with enthusiasm. He was keen to tell his story and had given thought to his presentation. He took the reins of the interview from the outset and appeared to enjoy talking to me. The primary work of Colin's narrative was to tell the story of *a love affair which has lasted for 46 years*. It seemed important to Colin that I appreciated the strength of the couple narrative and what a good life he and Carol have enjoyed through illness and health. Colin performed the identity of a cheerful, amusing but thoughtful man, a loving partner determined to make Carol's last months as rewarding as possible. Colin drew upon his previous self-narrative as a juvenile carer to his disabled mother in caring for Carol since she became ill and drew on his family template in formulating his beliefs about family values and open communication patterns.

Colin's presentation and use of language in the interview worked to entertain and engage the listener and draw them into his world. His use of anecdotes and humour brought his narrative alive; he also used humour to pull back from expressions of sadness.

There was a notable difference between the tone of the interview and the journal. In the interview Colin mostly maintains a cheerful presentation and

gives a positive depiction of the couple's life together, particularly since Carol's lymphoma diagnosis. There is little expression of sadness, fear or loss, despite his acceptance that she will die. Colin speaks openly of plans for Carol's death and funeral but does not consider the prospect of life without her. In the journal Colin's written self allows darker reflections freer rein and expresses his fears and vulnerability. He speaks of the pain of losing Carol and the fear of losing his identity. Colin looks to the future with open eyes and a mixture of despair and optimism.

With the last journal Colin sent me an email, commenting on his experience of keeping a journal. He positioned himself as a fellow professional commenting on the process of the research and demonstrates self-reflexivity in noting the effect of keeping a journal on himself. Colin reports being prompted to hold onto thoughts and emotions which would otherwise drift away and to take a meta-perspective on them, thus promoting further reflection and processing in a reciprocal loop. Colin planned to continue with the journal. (The email can be found in Appendix XVII).

Deidre

Deidre is a 54 year old Irish woman from a large Catholic family, married to Dave, a Protestant Scotsman 12 years her senior. The couple have been together for 35 years, since Deidre came to England at the age of 18. They have two children, both in relationships and with children of their own. Dave was first diagnosed with cancer of the larynx thirteen years ago; since then Deidre has been responsible for inserting and maintaining the valve in his neck to enable him to talk. Dave's cancer returned within the last year but it was some time before he was diagnosed and treatment commenced. Cancer has now spread to other parts of the body. Deidre manages his personal care herself and there has been little input from domiciliary services so far.

The interview

Before the interview Deidre appeared uncertain but, as we sat down, became increasingly comfortable telling her story. She started by assuring me she was, *No good at this sort of thing,* but was an articulate interviewee, keen to get her point of view across. She appeared robust and unsentimental, her sadness expressed mainly when describing her children's lack of support. Dave was at home during the interview but in a separate room, we met briefly.

Constructing a summary of the narrative in Deidre's voice (Appendix XII) was helpful in drawing together the different elements in Deidre's story and giving an overall perspective. It was particularly useful in situating Deidre's identity and relationships in the context of her life story, highlighting some of the earlier narratives she draws upon in her current life. A summary in the voice of Deidre's daughter (Appendix XV) is described below.

The champion narrative

In this section I have used both content and process analysis to demonstrate Deidre's relational narrative as Dave's champion, fighting his corner to ensure he receives the treatment she feels he needs. These sections of the narrative are performances in which Deidre shows how she *holds her own* in the face of the all-powerful and often confusing medical system. In becoming the author of her account, Deidre became more confident and animated, claiming her sense of agency.

> *D. And I said, "Well, how long is this scan going to take?" And he said., "Well, I don't know, it'll be a while", and I said, "My husband's not well, he's, every time he stands up he falls down, he's lost more than three stone in weight within the last three weeks". It was ridiculous.*
> *L. So, you were sort of standing up for him?*

Deidre uses direct speech to bring to life an interaction between herself and hospital staff in which she enacts standing up for her husband when he is unable to do so himself. Deidre steps out of the enactment to comment upon it. My responses as an interviewer, here and below, are co-constructing Deidre's narrative as her husband's champion. In the following extract she describes exchanges with the ambulance crew and then hospital staff as she struggles to get Dave readmitted.

> *D. (to ambulance crew) "Please don't bring him into A&E and spend hours there", I said, "He's just been released today from the hospital and he shouldn't have been released", "We can't do that, we have to bring him to A&E". We were six hours in A&E.*
> *L. Oh dear.*
> *D. He had another scan, on the brain, and I said, "You're not sending him home?" and "Oh, I don't know". And I said, "I'll tell you what," I said, "I'm not taking him home. He's flaked out in there; he can't move. [...]*
> *L. You had to be quite assertive about it?*

Deidre's extensive use of direct speech again brings immediacy to the narrative bringing it alive for the listener and adding credibility to the story. She emphasises her resolve and strength, a woman to be reckoned with. Using another discursive strategy, Deidre recruits other voices into the account, in these examples a friend at work and her niece, Natalie.

> *"And my friend at work, she said, 'Something's got to be done', she said."*

> *"And I says to Natalie, 'They wants me to bring him home.' She said, 'No!'"*

These voices are brought in support Deidre's case, adding further credibility. Deidre sometimes switches from the past to the present tense.

"And he says, 'They're doing surgery in the morning.' And I says, 'No they're not!' And he says, 'Yeah they are, they said nil by mouth cos I'm going down for surgery in the morning, on my tumour'"

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"And she's kind of, 'Well, we have to have this meeting.' And I said, 'Well I know that,' I said, 'I'm not stupid,'"

This mixing of tenses, as Riessman (2008) has observed, adds to the vivacity and immediacy of the report. Deidre left school at 13, not uncommon in Ireland at the time, and was not confident in her literacy. More than once Deidre challenges the way she believes others perceive her. She reports telling hospital staff*, "I'm not stupid!*" at face value an assertive statement but perhaps holding within it the fear that she may not be respected by staff. In the next excerpt, when insisting that Dave should have a scan, Deidre describes overcoming her lack of confidence. In becoming Dave's champion, Deidre supports her self-narrative of strength.

"Yeah. I mean, I kind of shy away from a lot of stuff, but this time, I knew, I had to."

Deidre's insistence on another body scan may indicate that she remained hopeful of some improvement in Dave's condition while she acknowledged he is dying. Deidre expressed ambivalence towards hospital and domiciliary services and was particularly critical of the G.P. practice for the delay in referring Dave to hospital. She questions decisions about his subsequent care and complains that she is not always kept informed. These experiences and her reaction to them have informed Deidre's adopting the identity of Dave's champion. In doing so she is challenging the dominant medical discourse and sustaining her relational narrative of loyalty and support.

Performing competence

Deidre demonstrated another identity of strength, the competent coper. This identity draws on her earlier self-narrative as a care provider to her mother as a teenager. Here she performs her narrative of expertise.

> *L. Do you feel proud that you are able to do these things?*
> *D. I don't know, no-one's ever asked me that, they just call me a "self-changing valve", I go up to the hospital and they say, "Oh, she's a self-changing valve." And she did say to me one time, "Oh, we could do with you over here!"*

Deidre starts with description then moves into an enactment of a visit to the hospital where the staff value her proficiency. Rather than taking exception to being objectified, Deidre (prompted by my interventive question) told me proudly of the staff's acknowledgement of her skill; this contributes to her self-narrative as a competent carer and valued member of the team. She again recruits a third party into the narrative to emphasise her point.

> *"His niece said, 'Oh, don't do that while I'm here.' Even if I'm just cleaning it* (the valve)*, 'I couldn't do that.' And I'd say, 'Yes, sure, of course you'd do it if you had to.' And she says, 'No, I couldn't.' 'Well, I don't know what kind of human being you are,' I said, 'But I wouldn't want to see David all clogged up.'"*

By drawing a comparison with others Deidre highlights her capability and her ethical position. Drawing on a previous self-narrative, she explains that she had always been the sort of person who "*just got on with it*", whatever life might throw at her. She believed her experiences have made her a stronger person. Deidre positions herself as the active provider and Dave as the passive recipient of her care. The couple have faced his illness together.

Family care template: *"just getting on with it"*

Deidre described how her mother had been vulnerable throughout her childhood. The second youngest of eleven siblings, Deidre was one of the last at home.

> *"I took over the care of the house [...], my mother suffered from nerves, and she was always in the hospital. My father was an alcoholic and used to beat the crap out of her, and, but he stopped drinking. [...] I looked after her the last years of her life."*

Deidre portrays two of her sisters as being, "*very nervous people",* and in a family where others were less robust, Deidre adopted the identity of strength and stoicism. This early self-narrative of family care provider as a teenager has been drawn upon in her later life. Deidre constructs herself as a pragmatic, capable woman as she describes these past family difficulties. She *"just got on with it"*, much as she has dealt with difficulties in her marriage and her current care relationship with Dave. Deidre describes a strong sibling bond.

> *"We had nothing growing up, but we seemed to have each other, and if anything happens, we're there for each other, do you know?"*

The perception that this narrative of family support is not replicated in her relationship with her children today is a source of distress to Deidre.

Changing narrative of family expectations

One of the most poignant aspects of Deidre's narrative was her account of her children's lack of support since Dave became ill. Deidre expressed more emotion about the changed relationship with her children than about the imminent loss of Dave.

> *L. Do you see much of them* (her children)*?*

D. That's a very sore subject, I feel like they…, they were very close, very, very close...

Deidre expectations of loyalty are based on her previous family narrative and this has made the current situation with her children both painful and incomprehensible. She speaks nostalgically of her children's importance to her during Dave's first illness.

"The three of us were always together, always up and down the hospital, always. You know like, 'Let's get a bag of chips on the way home', or, 'Let's quickly go home –', Always, always."

Deidre's use of direct speech powerfully conveys the *small story* which represents the closeness of the previous family relationship and a sense of what is lost. The impact of Dave's previous illness was mitigated by the family bond but this time Deidre feels alone.

D. I can't understand my kids, why they've…. I just don't know, because we were very, very close.
L. Yeah.
D. I just…. (Sigh)
L. ...Mm, that sounds, painful.
D. Yeah, very painful. And they, I just can't understand, can't understand being gay, I just can't get my head round that.

Deidre struggles to accept her daughter's lesbian relationship, another disruption to her expected family narrative. While Deidre has tried to accept her daughter's partner, her disapproval is apparent. Her account highlights the communication difficulty.

"My daughter says, 'You don't ask us nothing, you don't tell us nothing.' I mean, what's the point? Why should I have to ask?"

Her expectation that her daughter should know what she needs without being asked could have contributed to the confusion and frustration on her daughter's part. Similarly Deidre describes seeing little of her son John but has recently discussed the issue with him again.

> *"As he was leaving, he said, 'Mum, just ask if you need anything, I love you, Mum, I do love you.' I said, 'I know you love me, John.' He said, 'But if you don't ask me, I don't know. [...]" So I thought, 'OK'. So I rang him, said, could he take his Dad to the hospital on Friday? So, he's gonna take us on Friday."*

This marks a change which may allow a different relational narrative to be constructed. John expressed a willingness to help and Deidre was more specific about what she needs. His uncertainty about what she wants from him finds an echo in Deidre's ambivalence towards domiciliary services; she portrays them as unhelpful but is unclear what she wants from them and takes pride in caring for Dave herself. This highlights the self-narratives of both independence and need.

Being distanced from her children when she is soon to lose her husband has been extremely painful for Deidre. She also feels the loss on Dave's behalf. Her repeated use of the term, *"What family? I don't have family."* underscores her sense of loss. Her family narrative of mutual support and loyalty is challenged by her children's behaviour but it has been difficult to recognise her part in any estrangement.

Constructing a narrative from the imagined perspective of Deidre's daughter (Appendix XV) provided an opportunity to explore different meanings in Deidre's narrative of her relationship with her children. This is conjecture but may have relevance for their current difficulties. The daughter may be aware of and disappointed in Deidre's disapproval of her current lesbian relationship and there may be generational and cultural differences in expectations of familial loyalty. She may be unsure of what her mother wants from her and Deidre's capability may suggest she does not need her daughter's support. All

these factors could be maintaining distance. These ideas do not negate Deidre's distress and sense of betrayal but underline the complexity of the family narratives of loyalty and support.

Narrative of vulnerability

Alongside her stoicism, Deidre has moments of fear. Much of this centres on uncertainty about her future after Dave dies.

> *"I didn't want to be thinking about it because it frightened me, cos I've never been on me own, and I've got no-one here, really; the kids got their own lives."*

Deidre's fear of the loss of a relational identity is heightened by the knowledge that she cannot rely upon her children for support. Sometimes Deidre is caught unawares by her fear.

> *D. But, I mean, I don't, I don't know myself what's to come, do you know?*
> *L. No, do you think about that much?*
> *D. I'll be alright, fine, then I could be doing the dishes, or doing something, and my stomach just goes, I think, "God, is this what's to come?"*

Deidre has no previous template to draw upon to be on her own. She also expresses fears about the present.

> *"I don't like going out too much because I get scared about what I might find when I come back, left on his own."*

> *"I'm just scared mostly of watching, [...] of finding him dead in the bed. He didn't harm me when he was alive, it's just watching."*

These excerpts suggest that Deidre fears death itself or perhaps proximity to her dead husband. Deidre does not discuss these fears with Dave or the rest of the family and uses the interview to give voice to her dread. At the same time she has begun to consider her future.

> *"I think that will be, in the end, I think in the end I will go back (to Ireland). But even if I got a smaller place, like, you know, from the council, and could afford it, and got longer hours of work, and if I could be in the same area, I think I could cope with that as well, you know?"*

As Deidre speaks of future options, in England or Ireland, she draws upon her self-narrative of *"getting on with it*" and regains some confidence. Contemplating the medium term future, where plans can be made and action taken, is somehow less frightening than the unknown territory of death.

The couple relationship narrative

Deidre portrayed the narrative of their relationship as including times of difficulty. The couple met when she was 18 and Dave 30. He had been previously married and had one estranged daughter.

> *"I always said I'd never marry a man like me father, but, my father drank and Dave drank, but you can't help who you fall for."*

Her description of *falling for him* is one of the few occasions when Deidre refers directly to her feelings for Dave. Despite her stated intention to create a different couple narrative from her parents this was not initially the case.

> *L. So, how was it in the early days together?*
> *D. It wasn't great, he was a drinker.*
> *L. OK.*

D. And I didn't see him for dust. I mean, I'll be honest with you, you want the truth? I wouldn't see him on a Monday, Tuesday, I'd see him on a Wednesday, have sex, wouldn't see him Thursday, Friday or that weekend.
L. How long did that go on for?
D. Oh, years and years.

The age difference, gendered discourses, Deidre's youth and migration may all have contributed to disempowering her in the relationship. Although Dave was not physically abusive, the early couple narrative has parallels with that of Deidre's parents. The relationship deteriorated to the point that Deidre left Dave and returned to Ireland with her children. With the promise that he would change, Deidre decided to return to him. Catholic values in the family of origin narrative may have worked to discourage the break up of a relationship of a couple with young children. Deidre's action, informed by her self-narrative of strength, prompted a significant change in the couple narrative.

L. So, things changed then?
D, Oh God, dramatically, oh God, yeah, yeah, yeah... So, it was the best thing, he says to me, "It was the best thing you've ever done." Cos, I said to him, "You lost one family, Dave", and I said, "If you keep going, you're going to lose another family."

Their relationship improved considerably from this time. Deidre's decision to leave and then to return on her own terms altered the power balance between them
.
The couple narrative has again been reworked since Dave became ill. He relies upon Deidre physically and, with his work and social life curtailed, is increasingly dependant on her for companionship. When I ask Deidre about changes in the relationship she only comments upon moderating her behaviour towards Dave, suggesting past friction.

"No, we still get on the same, I still raise my voice. I talk loud, I've always done it, I said to him, "I'm not shoutin', I'm talking loud." But, I'm trying to back away, now. Before, I would fight my corner and that I can't do now."

Deidre sustains the couple narrative by continuing to *talk loud* but has tempered her behaviour on account of his illness. Deidre's couple narrative also incorporates her *getting on with it,* as described previously..

D. He's never had to look after me, I've always been alright. I just get on with things, if I'm sick, I'm sick. Still have to get out of bed, still have to cook and clean.
L. Yeah.
D. I've always done it, you know?

The relational narrative is supported by Deidre's self-narrative of stoicism and perhaps her cultural and familial gendered expectations. In response to a question about gender, Deidre responded as follows.

"I had to get on with it [...]. But I was just wondering, if it were reversed, would he be sitting in the pub? I don't know, and I'll never know now."

Deidre's delivery was neutral; she has apparently expected little support from Dave. At the same time she has joked with Dave about providing care in his illness.

"Like, it don't bother me, like, though. But I was saying to him 'I don't remember signing up for this, this wasn't in my marriage lines! (laughter) I don't remember saying anything about this!' You know, we laugh, I just laugh about it, he knows what I'm like, you know."

This exchange is indicative of how the couple use humour. Deidre self-identifies as a carer and has recently received the carer's allowance. This has

made a significant difference to their life in practical terms and is an official acknowledgement of her role.

Despite Deidre's openness it was hard to get a sense of the nuances of her relationship with Dave. She did not refer directly to her feelings for him, either negatively or positively. Perhaps this kind of talk was not in her repertoire. She did, however, speak of him with compassion and reported being tuned into his feelings, mirroring them on occasion.

> *D. Well, when he gets down, I get down. And then, if he seems alright in the day, then I'll feel good.*
> *L. So you react to him?*
> *D. Yeah if he's feeling down, cos it's heartbreaking, it is. My sister keeps saying, "Oh, you don't want him to live like that". Well, no I don't, but then I don't want to lose him either.*

The couple do not often share feelings and, while they may be protecting both themselves and each other, it is also a reflection of their habitual interactional pattern. Deidre tries to encourage Dave to think positively about his treatment options, but is trying to cheer him up rather than believing in the possibility of a positive outcome.

> *L. Do you talk to each other much, about how you're feeling?*
> *D. Not really, no. I kinda get scared.*
> *L. Yeah.*
> *D. I don't know, he just, last week he just, when he walked into the bedroom I said, "Well, next week your chemo'll be on Tuesday, and we'll see what happens with that", and I said, "You know what, David, the doctor says, if the chemo's not working, they'll try the radio again," I said, "You never know"' and he says, "Well if that don't work, then it's God."*

Deidre portrayed a strong and enduring bond in their couple narrative, with both warmth and humour. She demonstrates her loyalty and affection for

Dave not so much in what she says but in what she does, fighting his corner and caring for him as best she can.

Summary

In her account Deidre constructs herself as a woman who has endured hardship and difficulty but triumphed over it. Her identities of *champion* and *competent coper* draw on her earlier self-narrative as a family care provider. The *Narrative of vulnerability* and *Changing narrative of family expectations* portray other aspects of how Deidre constructs her experience and relationships. The emotional focus of the interview was in Deidre's account of the loss of closeness and support from her children, this running counter to her family and cultural narrative of how families should behave towards each other.

Deidre acknowledges the difficulties in the couple narrative alongside her account of an enduring affectionate bond expressed through action not words. She has accepted that Dave is dying and begun to consider the possibilities of a future life, although she is fearful of contemplating both the death and the loss of relational identity, being alone for the first time in her life. Deidre used the interview to review her life and express aspects of herself and her relationships in a way that she may not have done before and apparently found the experience cathartic. At the close of the interview she expressed her relief at having told me her story.

> *"So that's fine, that is. That's the longest I spoke for a long time, I feel good that I spoke about that now, and that kinda helps as well, it does, you know? Kinda off your chest."*

She explained that the reason she could be so open with me was because we would not be meeting again. Deidre's conversational style, using numerous examples of direct speech, brought her story alive and painted a vivid picture

of her life through this difficult time. Deidre did not keep a journal. Dave died a few weeks after the interview.

Estelle

Estelle is a 43 year old woman from Madagascar who has lived in England for 12 years; she has been married to Evan, a 50 year old Welshman, for 10 years. Estelle works as assistant to a company director. The couple have two young adopted children. Evan was diagnosed with cancer 18 months ago, by which time he already had metastases on the brain.

The interview

The interview was held in Estelle's home; Evan was not present, having been admitted to the hospice. Estelle was friendly and welcoming but appeared stressed. She had rushed home from work and already put a cake in the oven for the children after school. There was time pressure: Estelle had to finish the interview in time to collect the children. The phone rang several times in the course of the interview, Evan calling from the hospice. Estelle was rather short with him on the phone and I felt uncomfortable about being the cause of her not having time for him. These competing demands on Estelle's time are representative of her life at the moment.

For the first half of the interview Estelle gave a positive portrayal of the couple's closeness and harmony. I felt a disconnect between this account and the strong feeling I was picking up from her. In the later part of the interview, as she relaxed with me, she was more explicit in expressing her anger and to a lesser extent her sadness. I was very aware that she has to find a way of surviving, has to keep going. Estelle's first language is French but her English is fluent.

The "Interview tone" for this interview can be found in Appendix XI as an exemplar. As with all the "Interview tone" documents, this was an initial step to identify key elements in the interview, such as: What identities are performed? What is the work of the narrative? What is missing from the narrative? All of these helped in the initial stages of the analysis and are represented in Estelle's narrative. A letter written but not sent to Estelle can be found in Appendix XIII as an exemplar. Writing the letter helped me to think about Estelle's narrative as a whole and to view her current experience in the context of her life story. It also clarified my relationship to both Estelle and her narrative.

The *blow-by-blow* narrative

Estelle gave a full account of the progress of Evan's illness, investigations and treatment, from the time 18 months previously when Evan first experienced symptoms. Estelle framed the cancer and treatment as something that she and Evan are facing together. Upon receiving the terminal prognosis, Estelle adopted multiple positions: trying to be practical and problem solving and not wanting to accept the reality of the news. It was important to Estelle to give a coherent, chronological account of the trajectory of the disease and treatments and the couple's experience of them. It mattered to her that they trust and have a good relationship with the clinicians responsible for Evan's care and that she is fully involved in the decision-making process.

Since diagnosis, Evan has had periods of remission but his condition has continued to deteriorate. He has been subject to multiple seizures since undergoing brain surgery and the steroids used to control his pain have had severe side effects. His current hospice admission is to address these problems and perhaps to give Estelle some respite.

Narrative of motherhood

The most poignant feature of my interview with Estelle was her story of trying to be a good mother through Evan's illness and preparing her children for losing him. Estelle had tried for a long time to become a mother before deciding upon adoption. When Evan first became ill the children were very young and their son had been adopted only six months previously. The family had little time to settle together before having to deal with disruption and loss. Estelle is sensitive to the impact of losing a parent upon children whose early lives have already been disrupted.

> *"Because they are adopted children, as well, they've got this new Daddy, with whom they've bonded and now, you know, their Daddy being taken away."*

Estelle's narrative constructs the couple as active co-parents and this may be informed by having undergone intensive preparation for adoption, also reflected in the language used to describe the children's progress. Following recommended practice, they have been open with the children about their history and have used the same strategy regarding Evan's illness.

> *L. How much do you tell the children about what's going on?*
> *E. They know everything, at this stage. I mean, right at the beginning, we didn't say much, because we were trying to get our heads around things, we wanted to be sure what was going on, and what was the prognosis. [...] We wait a little bit, but now they know Daddy's got cancer, Daddy's very ill, that the doctors are trying to do their best to keep him alive, but there might be a time when, you know, Daddy won't be with us.*

Estelle has considered how the children's ages affect their understanding and gauged when and how much to tell them.

E. She (her daughter) has said, on quite a few occasions, "I don't want Daddy to die." And I don't know what to say. I said, "It's not going to be just yet, hopefully Daddy will have a bit more time with us." But then I also say... it's difficult to know what to say.
L. Yes.
E. But then I also say, "Daddy's always going to be with us, even if he's not with us physically, he's always going to be your Daddy, and he's going to be in our heart for ever."

Estelle balances transparency with reassurance, couched in terms the children can understand. She expressed powerful, contradictory feelings about the prospect of raising two children on her own, her faltering speech indicating her emotion.

E. All that has happened, it's been a lot, I can't count the number of hospital stays there has been, emergency calls, ambulance.
L. Mm, it sounds a bit of a roller coaster.
E. It has, completely, especially with two young children, I think it's, it's tougher. Sometimes I said, I do say to Evan, "If only I knew, perhaps…. I wouldn't have…, thought of, I perhaps wouldn't have adopted, if I knew you were going to be ill", but then, I know I just say that, perhaps because I am angry, or because I'm having some kind of feelings….
L.... Angry with what or whom?
E. Just because I'm going to be, having to raise…, angry at him sometimes, for leaving me, for having to raise these children, as a single Mum, which is not something I had in my plan, nobody has that, it's um… But then, I love those children so much, and we both love them so much. It's just a split of a second you just think, when you're very angry, and you say, "I just wish, if only I knew, I wouldn't have had them", but then I say to myself, "How come, how?" I mean, they're everything to us, they're everything to me, they're everything to Evan.
L. Yes.

E. I mean, perhaps we wouldn't be able to do that, without those two children, to go through Evan's illness. So I think having those children has helped us in a way, give a purpose to life, give a purpose to the fight we are having, we are going through.

It is apparent how difficult Estelle has found the last few months and her anguish at being left to raise the children alone. Although logically she cannot blame Evan for his illness, she still feels anger towards him. Estelle is not only faced with losing the father of her children and her partner but also the loss of their imagined future as a couple and family. Her expected and longed-for narrative has been disrupted. The intensity of feeling may be connected to the other narratives of loss in Estelle's life, her father as a teenager and her mother very recently. Her previous failed marriage and perhaps her inability to conceive also represent disruptions from her expected narrative. These are the backdrop to the happy family narrative which Estelle and Evan were constructing together, now this faces disruption.

Estelle pulls back from speaking of these difficult feelings to emphasise how much she loves her children. Framing parenthood as protective, she emphasises that the children help them endure this period and give meaning to life. In so doing she sustains the couple parenting narrative. Estelle's identity as a devoted mother is a survival narrative for now and the future. Closely connected to Estelle's feelings of anger and blame is Evan's sense of guilt at leaving her.

"But they (the children) feel secure in our, you know, with us, in our environment. So, Evan feels guilty that he's going to leave them and, you know, to leave me with them. [...]. He feels guilty about putting that on his family, he feels guilty about putting that on me."

Estelle moves between expressing compassion for Evan's guilt and contributing to it when she is upset. She understands his position yet expresses anger towards him.

The couple relationship narrative

Estelle initially gave a positive account of the couple relationship. They met 10 years ago when Estelle came to England to make a fresh start following a contentious divorce and married when Estelle's student visa expired because Evan didn't want to lose her. Estelle describes the relationship prior to Evan's illness.

> "A *very, very close couple, Always very close. I mean he's a very nice, soft person, really nice person, very tolerant, so I'm the one that would make most of the decisions."*

Evan's job was demanding and involved frequent travelling. Estelle describes her role in supporting him and running the home as informed by her cultural background, women adopting traditional gender roles in Madagascar.

> L. *Do you think your relationship with Evan has changed since he became ill?*
> E. *Um…, yes, I suppose it has as a relationship, as a husband and wife, it's not the same, but we still love each other, we still care about each other a lot, and I still need him for everything I need to do, advice, you know, I need to call him to ask him about it, I don't do anything before asking him first.*

Estelle shows how the couple are sustaining their previous relational narrative, focusing mainly on decision making. As Evan became ill he began to lose some of the power and status associated with his work identity and health. By consulting him Estelle is preserving his identity as the man of the family and maintaining the previous couple narrative. Estelle emphasises their closeness and openness with each other; at the same time there are issues which have been too difficult to discuss, particularly concerning Evan's death and Estelle's future on her own.

L. *Do you think about that* (the future) *very much?*
E. *No, no, I don't want to go there.*
L. *You don't want to go there?*
E. *I do, sometimes you have to think about it, you can't help it, for decision making, for things, but I don't intentionally go there, and think, "What's going to happen, how am I going to manage this, what am I going to do with that?" I don't, because it's too, too difficult. It's not a place I want to, I think it will prevent me to do what I have to do now.*
L. *Does Evan worry about what's going to happen to you?*
E. *Yes, I think he worries, he worries. He doesn't, I think he doesn't talk too much about it, because I think he thinks, um, hoping that he's going to get better, he doesn't talk too much about the funeral, things like that.*

The couple are protecting themselves and each other from the painful realities of the future, they are living with both worry and hope. Estelle suggests that Evan is in denial about his prognosis while she acknowledges the reality but avoids thinking about it. She positions avoidance as a survival strategy..

As the interview progressed Estelle spoke more openly of changes in the couple relationship. As Evan's condition has worsened, she has gradually taken on more responsibility, sometimes surreptitiously. Estelle, drawing on earlier self-narratives of surviving adversity, feels she has become a stronger person as a result but it has also led to friction.

"Yes, sometimes he doesn't accept it, sometimes he thinks, "You're doing things without con…." So we have a bit of, especially if he's on a high level of dex, the steroid, so he gets very irritable, change of personality, he just become very impatient, then we will have rows, we have had rows, you know."

The changes in Evan's personality due to medication represent a challenge to both individual and couple narratives. It is difficult for Evan to maintain the

previous couple relational narrative. He no longer cares for his appearance or what is going on in the world and Estelle finds him both oversensitive and irritable, all of which is in contrast to his previous character.

> *"And now I find it a bit difficult to, to accept, and adapt to his new way of thinking, because, why would he care? Because he's dying, he's got only six months to live, you know, why should he care about things?"*

She finds Evan's altered state hard to accept, representing as it does the loss of the man she loves as he was and the loss of their previous couple narrative. At the same time Estelle shows empathy and compassion for him.

Narrative of endurance and resilience

At the time of the interview Estelle was not only caring for and supporting Evan, looking after the two children and running the home, she was also working almost full-time. This is taking its toll on her.

> E. *And that's why I'm doing it, because I have no choice, what can I do? I've got two children, and I've got to get up every morning whether I like it or not. There are days when I just don't want to get up; I really don't want to get up. Not even for Evan, and I have to drag myself out of bed, most of the time because he's in so much pain. I have to give him some pain killers at 3 or 4 o'clock in the morning or 5 o'clock because I've got no choice.*
> L. *Do you ever feel resentful?*
> E. *A little bit, I don't let it dominate my mind, cos I don't think it's constructive for me.*

Estelle appears to gain some relief in expressing herself as she struggles to reconcile her relational narrative of a compassionate, supportive wife, with her

feelings of resentment and exhaustion. She draws on the previous narrative of her mother's illness to understand her reaction to Evan's needs.

> *"I could see how bad she was, how difficult, and we both, Evan and I, said sometimes we thought she was making it up a bit, to get a bit more attention. But then, she was very ill, and she was a very strong woman, my mum. So, I know, Evan, when he complains, it's real, I know."*

Estelle reassesses her account of her mother's illness. Reconstructing this narrative enables her to counter her resentment towards Evan and to retrospectively value her mother's strength. She draws on previous experiences of surviving loss and overcoming difficulty to construct her self-narrative of resilience.

Estelle has used a number of coping strategies. She decided to keep working; this continues to support her self-narrative of strength and competence.

> "*I think it helps me to get dressed every morning, if not I'd probably be in track-suit bottoms all day, perhaps not having a shower, I wouldn't care about my appearance. Because I have a job I have to look after myself a bit, and I like looking after myself."*

Working maintains Estelle's identity as an independent woman outside her roles as wife, mother and carer. It has provided a reason to look after herself, continuity and certainty at a time when so much has been in flux. Estelle values occasionally making time for herself as a woman, in the knowledge that life may become even more difficult. Here she is describing shopping.

> L. *...To do something that's just for you?*
> E. *Yes, something that's just for me, and I think that helps, that has helped me enormously, to take my mind...Cos I know Evan is dying, but at the same time, life continues, and I'm not saying that*

because…., it's going to be horrendous, when he's not here, it will be very, very difficult.

Estelle acknowledges that Evan is dying but she must keep going for the children and for herself. The timeframe of her life with Evan is limited but her life with the children will continue. Estelle has no family in England but her sister's unconditional support by phone has been a lifeline, particularly since her mother's death last year.

"I can tell her anything I have on my heart; you know, if it's anger, if it's happiness, if it's moaning, I know she will listen. [...]It's good to have this relationship".

Estelle emphasised the closeness of her relationship with Evan but, with his illness and current irritability, it is difficult to confide in him. The relationship with her sister allows expression in her mother tongue and provides continuity. Estelle recently started meditation.

"Meditation definitely helps, it's stillness, a quiet time, because life is so busy. [...] So, spiritually, I think it helps the mind."

Meditation is another way in which Estelle takes care of herself to enable her to sustain her self-narrative of resilience and continue to perform the identity of the survivor. A further strategy she has used is to be well informed about all aspects of Evan's illness and the side effects of his medication. Becoming knowledgeable restores some sense of agency and control to Estelle at a time when she feels powerless and overwhelmed.

Part of Estelle's motivation for taking part in the research was her sense that the carer's voice is not always heard.

"I always feel for all those carers out there who must, people don't give much consideration sometimes, people ask, "How are you

doing?" to the person who is ill and I think the job of the carer is the most difficult job, that could exist! It's really, really tough, actually."

This perhaps speaks to Estelle's wish to have her own voice heard.

Summary

Evan's cancer occurred at a particularly difficult time in the family life-cycle; the expected narrative has been disrupted. Evan and Estelle are relatively young and had little time to settle their adoptive children into the family before facing upheaval and loss. Estelle's imagined future of family life was barely realised before it was lost; she now faces the prospect of raising their children alone. In losing Evan she is losing her partner, the father of her children and her imagined future narrative. Estelle's previous narratives of loss inform her current experience.

The work of Estelle's narrative is to address and find meaning in the confusion and contradictions of her life, relationships and identity at this turbulent time. Preserving her self-narrative of the good mother helps Estelle to survive and gives meaning to her life. She is sensitive to the needs of adopted children and uses all available resources to prepare them for losing their father, at the same time she questions the decision to adopt them. Estelle works to preserve the couple narrative; she portrays a close and loving couple relationship, facing Evan's illness together. The performance of the devoted wife caring for Evan physically and emotionally is in contrast to the less privileged narrative voice of anger and resentment also expressed. She is aware of the enormity of losing Evan and avoids focusing on it, fearing this could jeopardise the present.

Drawing on a self-narrative of resilience, Estelle presents herself as a pragmatist, dealing competently with the practical issues of her current life and using what survival strategies she can. At the same time it is hard for her to contemplate the full reality of a life without Evan. Estelle used the interview

to give voice to painful feelings. The fact that she agreed to take time to be interviewed in her busy life is indicative of her desire to have her voice heard. She was valuing of the interview, describing it as *"cathartic"*, and hoped that her experience might be of use to others. Telling her story engenders a sense of agency and helped her order and integrate an overwhelming upheaval in her life.

Estelle expressed a wish to write a journal but was unable to do so because of time pressure.

Valerie

Valerie is a 71 year old Anglo-French woman currently caring for her Russian partner, Maxim, aged 64. The couple have been together for 26 years and are not married. Both were previously married and neither have children. Valerie has led a varied and colourful life and lived and worked in several different countries. The couple lived in Russia until 10 years ago when bankruptcy and ill health prompted a return to the UK. At this time both were alcoholics, Maxim was suffering from Multiple systems degeneration and Valerie had Chronic obstructive pulmonary disease. Maxim was diagnosed with cancer 15 months before the interview, followed by the discovery of secondary tumours. Valerie herself is dependant upon oxygen, to which she must be connected most of the time, so her freedom is compromised irrespective of caring for Maxim.

The Interview

The interview was conducted in the lounge area of the sheltered housing complex where the couple live. When Valerie came to meet me I was struck by how frail and ill she appeared, walking with some difficulty and looking older than her years. She was welcoming, charming and frank about her life.

She was eloquent and thoughtful in her answers and often amusing. I did not meet Maxim but he was aware of the interview and had no objection to it.

The sensitive caring partner narrative

In this section Valerie performs the identity of the loving partner, caring physically and emotionally for Maxim. Since Maxim's condition worsened and cancer was diagnosed, Valerie has managed all the physical tasks in the home, despite her own ill health.

> *V. And men were the ones who were doing the helping always, weren't they? So I think it strikes them, psychologically, much worse.*
> *L. Yeah.*
> *V. If he can't work, he can't support, he can't cook, he can't feed me, he can't please me, what can he do?*
> *L. Have you seen evidence of this?*
> *V. Yes, I have. Which is why I work very hard, emotionally, to be sure that he doesn't feel like that, and I don't think he does really. I think he's perfectly happy that I'm contented.*

Valerie's age, upbringing and Maxim's nationality may be informing Valerie's perception of gendered roles. She is sensitive to and protective of his masculine identity at a time when he has limited options for performing it. Her task, as a woman, is to ensure that he feels good as a man. In doing so Valerie sustains the couple narrative and gendered positions. She prioritises Maxim's enjoyment over her own need for conversation.

> *V. He can become downhearted; [...] he'll go very quiet. But he's not a very expressive person, anyway, you know, he doesn't talk a lot.*
> *L. Mm.*
> *V. He'll absorb himself in his computer, which is good,*

L. Yes.

V. It takes you out of yourself, I think. And that's fine. And I'll want to say something, and he'll say, "Don't say anything, don't talk to me, don't talk to me!" Because he's reading it in English, which is his second language for him. And I find that quite frustrating, that I can't have a conversation with him because he's doing something else, but then I have to remind myself that the whole point is he should do something which he's enjoying.

This may represent an enduring couple narrative or Valerie may now be consciously making allowances for Maxim's illness. She takes a positive perspective: minimising her frustration and sustaining her relational narrative as a compassionate and selfless partner. She protects him from her sadness.

L. Do you have times of sadness at the moment?

V. Yes, I do, but I don't do it in front of Maxim, I try to keep it away from him.

L. Mm.

V. If I feel like crying, then I'll go out and cry, cry somewhere else, I don't need to, I'll cry in front of him as well, obviously, because we're very close, but, not to be too morbid about it. I don't think it helps him.

Valerie demonstrates a tension between their closeness, coupled with her self-narrative of transparency, and her need to protect Maxim, sustaining her relational narrative of care. She describes her *artificial guilts*: the term notable because it suggests that, although she may feel guilty about being unable help him more, she is aware the guilt is not justified.

V. I get the artificial guilt that I'm useless; I can't cook, I'm not doing anything to help him, I'm not taking his pains away. [...]

L. And do you share those "artificial guilts" with Maxim?

V. I talk to him, yes I do, yes.

L. And how does he react to that?

V. "Rubbish! I wouldn't be without you, just being here is all that matters."

L. Yeah.

V. You know, that's all, right.

L. And does that reassure you?

V. Yes, but I still feel it; I still do feel artificial guilt. And he gets like, "Oh, it's me, I'm causing you trouble," a little bit, the same thing, you know, and I say, "No Darling, you're not! I love you, you know. I love you even if you were being horrid; just try not to be horrid!"

Valerie shows how the mutual expression of *artificial guilts* prompts conversations in which each partner is able to value the other, sustaining their couple narrative of mutuality. The use of direct speech brings this exchange to life. Valerie relates this interaction with amusement and, while indicative of mutual unconditional love, it could be understood as affectionate banter or suggest friction in the relationship. It can be difficult to acknowledge or express negative emotions towards someone who is dying.

Performing transparency

Over the course of the interview, Valerie referred several times to her self-narrative of transparency.

V. You know, no secrets, we don't want secrets, not with your nearest and dearest, I think that's silly. And besides, that's a decision I made in my life a long time ago; "The truth, the whole truth and nothing but the truth."

L. What prompted that?

V. Oh, probably one of the divorces, I would think, probably the first one, I would think, yes, because he was a right bastard.

L. Mm.

V. I can't stand lies, I can't stand, you know, prevarication.

Valerie's self-narrative of truth and transparency has been constructed in the context of having been deceived herself. It is also apparent in her acknowledgement of Maxim's prognosis; she faces the future with open eyes. Below Valerie elaborates on the change in the couple's lifestyle when they returned home from Russia. She does not share Maxim's sense of shame.

> *L. Was it a conscious decision, not to pick up social contacts when you came back?*
> *V. Well, yes, on his part, definitely. He didn't want anyone to know that he was, um, on benefits, basically. I mean, I don't advertise the fact, but it didn't bother me if people did know. [...] I gave up caring about people who care about things that I do not agree with, their opinions are of no value. [...] But, it does cut down enormously on the number of people you know.*

Valerie does not dwell on the negative aspects of this life change. Her life story, from early losses, through abusive relationships to recent experiences of loss and illness, has heightened Valerie's awareness of her priorities, what is valuable and what can be relinquished. She can be considered to be drawing on *quest narrative* (Frank, 2010) constructing surviving adversity to gain wisdom and understanding.

Valerie's transparency was enacted in the interview, she was frank about all aspects of her story. She related the details of her life with some relish, demonstrated by the use of colourful language, metaphor and humour in her account.

Drawing on past narratives

Valerie draws upon past self-narratives and knowledge gained through experience to enact the identity of the brave survivor of life's ups and downs: a narrative of resilience.

L. It sounds as if you (Valerie and her sister) *went through a lot together, as children.*
V. Yes, we did, yes, yes. Yes, it's quite interesting, it's quite a..., I think perhaps it's all part of, there's always the benefit in the bad, isn't there? Or the silver lining or whatever, but I think, having experienced so many people so close, dying along the way.

It is clear how much Valerie continues to think about her life; she draws upon past experiences of loss and survival to navigate the present and reinterprets the past through the lens of the present. Valerie presents as determined to construct a positive narrative of her experiences of loss. She describes a series of bereavements, including her father at 8 her mother at 11, her fiancé, a pilot, killed when she was 16, followed by both grandmothers. She and her younger sister differed in their reaction to loss.

"You know how geese sort of fix on something? And, to a certain extent it was me and my, our nanny, that my sister fixated on, but I didn't, I didn't fix on anybody, really. I was just that much older to handle it on my own, somehow."

Having lost both parents, then being in the care of an *Edwardian* grandmother and a convent, Valerie drew upon one of the few cultural templates available to her, the self-reliant survivor. This identity brought its own satisfactions and Valerie values her resilience

L. So, having experienced all these losses, how does this relate to how this period is for you?
V. Well, I think it's certainly taught me that you, you know, that the pain passes, it does, and you do get over that.
L. Mm.

V. I'm a bit of a "white queen"[3] anyway, you know the white queen, I seem to cry in advance, which is not such a bad thing to do, you know. And I, I don't know how sad I will be.

L. Mm.

V. I'll be bereft, of course, but, it will pass. Because I know that, it will probably pass more quickly than it would for someone else.

Acknowledging that she cannot predict her reaction to losing Maxim, Valerie prepares herself by grieving now and emphasises her acceptance of the loss. The following excerpt demonstrates how Valerie and I co-construct her identity as the adaptable survivor. The term *acting* suggests a belief that consciously behaving in a particular way has facilitated her adaptation.

L. Are you surprised at how you've adapted to the different way you're living your life now?

V. No, not really, no. I'm pretty good at adapting, I was always very good at acting, and I think my life has been…so many different things that I've done, you know.

L. Mm.

V. And I've always enjoyed all of them, and adapted fine, running companies in America, running companies in Russia, running companies in France, running houses in two countries at once. I used to be in the building trade at one point; I even did a stint of striptease in Soho in the sixties!

L. Really!

V. And, you know, er, amazing, the things that I've done.

L. Mm.

V. So adapting, is one of the things I do.

L. That's one of your fortes?

V. Yes, exactly, that's one of my fortes. And I think, without that, I would have found it very much more difficult. Yes, I could quite easily have flapped my wrists a lot, and copped out.

[3] The White Queen is a character from Lewis Carol's "Through the Looking Glass", who, because she is a reflection, experiences emotions before rather than after the event.

Valerie welcomed the opportunity to narrate her previous life. It brought pleasure to relate her varied and colourful past, a reminder of other self-narratives for herself and for me. The phrase, *flapped my wrists a lot and copped out,* describes a position Valerie rejects. She prides herself on her strength and adaptability. Valerie draws on an earlier narrative to explain her relationship to duty.

> *V. ...You have responsibilities, and if you take on a job, or a responsibility, or whatever it is, you do it to the best of your ability, for as long as it has to be done.*
> *L. Yeah.*
> *V. And that's that, there's no good complaining about it, you just enjoy doing it.*
> *L. Yeah, yeah.*
> *V. And your enjoyment comes from doing it well, even if it's a thing you don't like, so to speak. I'm putting it very harshly, but that was definitely, sort of, the Catholic convent ethic... Definitely with the generation gap, my grandmother being an Edwardian, don't forget, you know, it was raising one to be wife of a successful British gentleman.*

Valerie has taken ownership of the narrative that fulfilling one's duty well can bring satisfaction and even enjoyment. She speaks wryly of the cultural template provided by her grandmother which does not fit with how she has lived her life. Her mother had challenged these values by marrying and then separating from Valerie's father, a Frenchman. At the time Valerie was coming of age in the 1960s, traditional social mores were being challenged and she has lived a life which would have been difficult for previous generations; embracing some cultural values and rejecting others: Valerie's self-narrative is constructed on her own principles.

In contrast to the adaptable survivor portrayed above, Valerie describes herself as *depressive* and has been on antidepressant medication for much of her life.

> *V. I'm also diagnosed as depressive, you know, which is hardly surprising, given one thing and another. That was not due to his (Maxim) being ill, that was before he was ill. I've been depressive since my last break-up, which really affected me really badly, um, er…, so that kicks in sometimes.*
> *L. Mm, have you had any treatment for this?*
> *V. Yes, I'm on some kind of pill that I take every day, which is supposed to be antidepressant.*
> *L. Mm.*
> *V. I'm assuming that it vaguely works; otherwise I would be crawling around, crying.*
> *L. Do you think that Maxim's illness has affected your depression?*
> *V. Well, er, (pause) I suppose it has, it adds to it, yes, yes. Yes I am a, sadder person than I was before.*

Valerie's phrase, "*crawling around, crying",* suggests a less than sympathetic position on her grief. She attributes the start of her depression to earlier losses.

> *"I think the depression started before, when my fiancé was killed, and it was never addressed, if you see what I mean, er, but if it had been addressed at that point then maybe I wouldn't need medication now, [...] It sort of never went away, it was always just there."*

Valerie proposes an unrealised narrative, regretting the imagined life she could have had if only her depression had been diagnosed and treated earlier. Her sadness has always been with her as a subordinated narrative.

The couple relationship narrative

Valerie and Maxim have lived together for 26 years. Both had several previous partnerships. Valerie's previous relationships ended badly and at least one partner is described as abusive. Valerie and Maxim met at a party in London.

> *"I thought he was very good fun, and very good company. He said it was a 'coup de foudre'; he was in love with me, (finger snap) like that."*

Valerie describes them as a very close couple, perhaps soul mates, who share many interests and have enjoyed a good life together as life and business partners.

> *"If I hadn't been me, I'd have been him, you see, it's like an alternative to one's self. We're very similar, in many, many ways, very different in others."*

> *"We've laughed our way through 26 years of it, and, um, yes, a very good time, yes, very good. I can't think of any downs, really. If there were any, it was down to booze."*

The couple narrative portrayed is one of resilience, characterised by mutual support and affection through good times and bad. They have survived bankruptcy, illness and alcoholism, which Valerie hints may have caused problems between them but did not elaborate. The affectionate banter described may or may not have been indicative of irritation on Maxim's part. Overall Valerie chose to represent the couple relationship in positive terms; the overarching narrative being of strength and closeness through adversity. Perhaps so close to Maxim's death she did not wish to contemplate any negative aspects of the relationship.

Valerie draws on multiple narratives in her construction of gender in relationships. She has rejected the cultural template of marrying a *successful British gentleman* and has had several relationships but, drawing on traditional gendered discourses, believes men need to be looked after and that helplessness is more difficult for them. Valerie works to bolster Maxim's male identity and sustain the balance in the couple narrative now that he is disadvantaged.

Maxim has become increasingly dependent on Valerie, both physically and emotionally. Sustaining the couple narrative of mutuality, she also acknowledges her dependence upon him.

> *L. So, how much help do you have to give to Maxim on a day to day basis?*
> *V. Well just being there 24/7 I think is important. Psychologically it's extremely important to him that I'm there, and he's, er, kind of lost without me. As indeed I feel pretty miserable when he's not around, you know. We're really used to being around each other, and it feels like you've lost an arm or something when the other person isn't there.*

The mutual dependence and the comfort Valerie takes from Maxim's proximity suggest that Valerie will find losing him very difficult but she privileged her narrative of acceptance and adaptability over the narrative of loss.

The Journal

The narrative of the journal can be viewed as a *small story* within the context of the *big story* of the overall couple narrative and echoed some features. Valerie started to write the journal at my suggestion, but it became something of which she took ownership. The context of the journal, covering the last few weeks of Maxim's life and Valerie's admission to hospital herself soon after starting it, determines the content. The journal gave her space to express her

anguish at being separated from Maxim and her fear that she will not be with him at home when he dies. In the journal, as in the interview, Valerie performs the identities of the adaptable survivor and the devoted partner.

Valerie writes from her hospital bed.

> *"Darling M now two days alone!! And I don't think they will let me out until the w/end.*
> *I just hope he looks after himself men seem a bit hopeless at that.*
> *I miss him a lot."*

Valerie's primary concern was Maxim's welfare, recognising his dependence upon her physically and emotionally. She adopts a gendered perspective regarding Maxim's ability to look after himself. Her own health problems are viewed as an unhelpful distraction from her priority: taking care of Maxim in his final days, sustaining the couple narrative until the end.

> *"I'm no use to man or beast if I don't get sorted and I'm in the best place for that so enough bitching."*

Valerie recognises the necessity addressing her own health and draws on her self-narrative of resilience to manage this challenge to the couple's preferred end-of life narrative. The phrase *enough bitching* indicates self-censoring of her understandable frustration. Maxim's health deteriorated and he agreed to hospice admission.

> *"What a ghastly day. M called saying he felt weak and had bad pain [...] His actual words were – 'This is it', what bad timing – I must get better – I must be able to say goodbye properly – I want to be with him very, very much."*

> *"God I rang to talk to him and the 'duty' doctor had sent him to Charing X hospital. He hates hospitals. Anyway, I called the A&E doctor (ultra nice and kind) and he agreed with me that the 'Duty*

GP' was instinctively thinking save life instead of – how can we help him 'go' in comfort, no pain with dignity etc. So he sent him back to the hospice.

Valerie continues to perform her identity as Maxim's champion to avoid his admission to hospital. Sustaining this identity despite being hospitalised herself brought her some satisfaction. Her relational narrative of devoted care is preserved. Valerie's narrative is an acceptance that treatment is no longer appropriate, that Maxim is dying. Valerie is discharged and prepares for Maxim to join her at home.

"Spent the afternoon with M, nice almost like being at home just to sit 'next to' and hold hands [...] All I want is to be alone with M."

Despite the upheaval and uncertainty Valerie sustains the couple narrative of closeness, appreciating the time they have together. Maxim finally returned home.

"Well today was exhausting but I think it will all work out. It seemed at one time like rush hour at Victoria Station [...] and darling M just happy to be home. I cooked some chicken soup and he ate 2 wings and half a slice of bread and 2 big bowls of broth!! Great I felt really proud of myself."

Valerie's priority is that the hoped for narrative is restored: that the couple are reunited at home for Maxim's last days. Maxim having been a chef, food has been an important part of their couple narrative, so his enjoyment of her cooking is of particular significance to Valerie, an acceptance and appreciation of her care and love.

Valerie found keeping a journal through this intense period to be a positive rather than burdensome experience. She described participation in the study as 'cathartic' and thought she might continue to write the journal for herself. Three days after I collected the journal, Maxim died at home.

Summary

Valerie uses the interview and the journal to review her past life, value her relationship with Maxim and to process and find meaning in her current experiences. The context in which Maxim's cancer occurred determined its significance for the couple. They had already survived massive changes in their lives over the last 10 years. Individual and couple narratives had already been disrupted and adapted; both had accepted their future was limited before the cancer was diagnosed.

The couple narrative Valerie constructed was one of mutuality, love and resilience. Throughout their long relationship the couple have optimised the opportunities afforded to them, enjoying the good times and surviving difficulties as a cohesive unit. The couple have remained devoted to, as well as dependent upon, each other throughout the deterioration in their health and other life changes. The scarcity of alternative family and social support has reinforced this.

In the interview the self-narrative Valerie privileged was that of the valiant, adaptable survivor. Valerie was a compelling narrator: she has led a colourful life and her frankness, humour and language brought her story alive. She appeared to gain some satisfaction from the telling, valuing her life. She demonstrated self-reflexivity in her narrative and was realistic in her appraisal of her limited future with Maxim and future alone. Valerie's written voice is similar in tone. She brings immediacy and vivacity to her description of this critical period. Her devotion to and concern for Maxim is again paramount in the written narrative and she focuses on her priority, to care for Maxim at home when he dies.

Valerie's account portrays acceptance of losing Maxim. This is informed by her belief that death is not *the end,* her previous experiences of bereavement and her self-narrative as the adaptable survivor. The knowledge that she and

Maxim have already lived life to the full may inform Valerie's acceptance of the end of their life together.

Valerie's early experiences and available cultural templates have privileged a sense of duty, self-reliance and adaptability. At the same time, Valerie has struggled with depression and alcoholism for much of her life and remains on antidepressant medication. Her health is unlikely to improve and she has a relatively small circle of family and friends. Her courage, humour and adaptability will be put to the test as she faces life alone.

Summary of individual narratives

The six individual narratives presented in this chapter illustrate the range of ways participants constructed their experiences and relationships as they cared for their partner at the end of life. All of the participants were keen to tell their story and some seemed to gain relief from so doing. The purpose of this chapter was to focus in detail on each of the narratives before looking for similarities or differences across the cases. Nevertheless, some features were particularly notable in the accounts. All participants worked to preserve individual and couple narratives in the face of the terminal illness. All drew on previous narratives of resilience to manage this time. Acceptance that the partner was dying was complex, as was what could be discussed with the partner and how. Participants had used the time since the terminal prognosis to review and value the couple narrative. Most constructed a couple narrative of enduring mutual love.

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In this chapter I have presented a detailed analysis of the six individual narratives, including data from the interviews and the journals. The following chapter contains the cross-narrative analysis.

Chapter 6

The cross-narrative analysis

I have used two complementary methods of cross-narrative analysis in this study to highlight aspects which resonated strongly across the narratives. The first section of this chapter analyses narrative themes across the cases, drawing together some of the similarities and differences between the narratives. In the second section, following Frank (2010), I have identified a typology of narratives in the study.

Analysis of narrative themes

Predicted and disrupted narratives

How the news of a terminal prognosis was received by participants was determined by their life-cycle stage and narratives of the future. Although several participants described the terminal prognosis as *coming out of the blue,* the news was more unexpected for some than others. The age of the partner and the previous history of illness also informed how the news was received.

For couples such as Brian and Beth and Deidre and Dave the first cancer diagnosis was made many years previously and was followed by a period of remission before the cancer returned. This trajectory represents multiple disruptions to the couple narrative. A period of upheaval was followed by a return to a reconstructed couple narrative which still included a hopeful future. This was again disrupted by news of metastases and finally the terminal prognosis, a continuing series of blows to the expected narrative. For other participants, Anna and Estelle, the first cancer diagnosis included the news of metastases. This represented a sudden and irreversible rupture to the expected couple narrative. The narratives of these two participants illustrate

how the age and life-cycle stage can inform the impact of a terminal prognosis.

Of all the participants, Estelle felt the injustice of losing her partner most keenly. The couple were both relatively young (43 and 50) and, having recently adopted two young children, had had little time to fulfil their hoped-for family narrative before it was disrupted by Evan's illness. Estelle intimated that she would not have chosen to adopt had she known she would become a single mother.

"*... it is not something I had in my plan.*".

In contrast, Anna (67) positioned the loss of Anthony as an expected part of the life-cycle. This does not suggest the expected loss was not extremely painful but there was little anger or sense of unfairness expressed. Anna stated that, given the age difference, she had always expected to outlive her husband.

> *"You don't marry someone 12 years older than you without knowing that, as a woman, you're probably going to be the one that's left."*

Valerie (71) also accepted the loss of Maxim philosophically, this being informed by their life cycle stage and previous couple illness narrative.

Some of the participants, Valerie, Anna and Colin, utilised their previous couple narratives to contextualise the news of the terminal prognosis. All of them used the period since the prognosis to value the life they had enjoyed with their partner, the knowledge of this aiding acceptance. Colin, while portraying an acceptance of losing Carol, wished they could have had more time.

> *"All that's happened is the timing has gone, you know, we should have had another 15 or 20 years together."*

Brian's constructed Beth's terminal prognosis as an unexpected narrative. This was informed by her age and lifestyle: she was only 57, neither smoked nor drank alcohol and was careful in her diet. Brian's account highlighted his sense of injustice regarding her illness. His anguish at the disrupted couple narrative was expressed in the anger and stress he described.

Narratives of loss

Most of the participants had been with their partner for a long time, some over 40 years. Brian, Deidre and Colin had been in their relationships for their entire adult lives. All had, to some extent, formed their identity in relation to their partner. In losing their partner the couple narrative was being lost and their individual identity challenged. Valerie and Colin both compared the loss of their partner to a loss of a limb, loss of part of the self. Most of the participants referred to a fear of being alone.

Deidre, Estelle, Anna and Valerie all reflected on previous narratives of bereavement and how they informed their understanding of the forthcoming loss of their partner. Deidre had coped with previous losses with the stoicism performed in the interview. Estelle reworked the narrative of her mother's illness and death to increase her empathy for Evan. Anna contrasted the loss of a younger friend, an unexpected and untimely narrative of loss, with losing Anthony and took some comfort from his having lived a full and happy life. Valerie drew on previous narratives of loss which she believed helped her acceptance.

All of the participants had contemplated their future life alone, some with trepidation. Colin and Deidre had no previous template for living alone and the thought was daunting; at the same time both had considered possible future narratives. Brian, who had been on his own in the army, was unable to imagine a future without Beth. It was frightening for Estelle to contemplate her future narrative as a single mother. Valerie's and Anna's accounts suggested

they were not afraid of solitude, their self-narratives supporting this. While neither expressed fear for the future alone, their sense of loss was apparent.

Both Anna and Colin used their journals to consider the meaning of the loss of their partner. Anna described the significance of losing the person to whom one was the most important and beloved. Colin described the fear of not only losing his identity as part of a couple but of losing his value as an individual. In losing their partner, all participants were losing the person with whom they had constructed their individual and couple identity over many years. Their relational identity was threatened. They were losing the person with whom to revalue and reconstruct past narratives and co-construct future narratives: the continuity of their life-story was disrupted.

All the participants accepted at some level that their partner was dying. All knew intellectually they would one day be on their own but there was a wide variation in how much each could fully acknowledge the meaning of their partner's death. Acceptance was nuanced and altered over time and in how much could be shared with the partner. In Brian's account he accepted that Beth was dying but was, until very recently, unable to share his thoughts with her. In Anna's narrative she accepted that Anthony was dying and there was a marked difference between Anthony's serene acceptance and her narrative of *private grief*. Valerie's narrative was one of acceptance, her priority was to sustain their couple narrative until the end. In the interview Colin privileged a couple narrative of pragmatism and acceptance; his journal indicated a more complex personal narrative of loss.

For all the participants it was to some extent possible to construct a pragmatic future narrative: to make plans and consider the future in practical terms. What was more difficult to comprehend or accept was the idea of an absence, and the meaning of this for the soon to be bereaved partner's identity.

Spoken and unspoken narratives

This section highlights the multiple narratives utilised by participants regarding what can be talked about, how, when and by whom. For some couples it was a question of timing; conversations unthinkable a few weeks previously may become possible or necessary as the end approaches, as in the case of Brian and Beth. Several participants portrayed couple narratives of openness and transparency; at the same time, for all of them there were currently some *no-go* areas. These related to individual narratives of secrecy, often informed by a desire to protect their partner from the knowledge of the effects of the partner's illness and expected death upon them.

Anna, Valerie and Colin all particularly emphasised their couple narratives of openness and transparency. All three had taken up multiple positions to protect their partner from their distress and thus preserve the couple narratives of mutual care. For all of them either sharing or not sharing their emotions with their partner could support relational narratives of closeness. This depended on the context and their perception of their partner's health and desire to engage in discussion. At some level, all shielded their partners from their grief at the anticipated loss and fears for the future. Colin and Valerie both referred to individual narratives of truth and transparency based upon earlier narratives: Colin's was based upon his family script while Valerie's attributed her philosophy to her having been deceived in previous relationships. These self-narratives were sustained alongside protecting their partner.

Estelle and Brian's narratives highlighted how narratives of speaking / not speaking can alter over time. Both described the earlier stages of the illness where the diagnosis was faced as a couple and decisions made together. As the disease progressed it became more difficult for both couples to process the terminal illness together. Neither couple had a shared narrative for end-of-life issues and neither had broached the discussion of a funeral. Estelle could not yet contemplate aspects of the future herself and believed Evan was in

denial. This couple were protecting themselves and each other by their silence and not accessing the potential mutual support previously shared.

Brian had preserved his relational narrative as Beth's protector by shielding her from discussion. Beth opening the discussion about ceasing chemotherapy marked a change in the couple narrative of what could and could not be discussed and by whom. This change could have facilitated a shared narrative of end-of-life wishes. In contrast, Deidre and Dave had a shared narrative that Dave was dying and they had planned his funeral; discussing their reactions to the knowledge of his death had been more challenging. This may in part have been due to protecting themselves and each other but also reflected the couple's discursive pattern.

Drawing on previous narratives

All of the participants drew on previous self-narratives of surviving or overcoming past challenges to construct themselves as capable, resilient individuals as they faced the challenge of caring for a dying partner. Each utilised whatever skills and personal qualities they could muster to manage this period and improve their partner's quality of life. Deidre and Colin drew on experiences of caring for a parent and Anna, Brian and Colin drew on professional experiences. Valerie utilised her ability to adapt to new situations and Estelle drew upon her experience as a migrant. Most of the participants had also survived previous bereavements. At the time of the interviews each participant had been caring for their partner for many months. Over this period each had developed further qualities and competencies which could also be drawn upon to support self-narratives of strength and resilience.

Some of the participants' professional and personal experiences had been particularly helpful to them in caring for a partner at the end of life. Anna drew on her professional self-narrative using her therapeutic insight and self-reflexivity in understanding the care relationship and utilised the skills, gained over many years as a wife and mother, to care for Anthony now. Brian also

drew on his professional self-narratives in both caring for Beth and managing his own feelings.

> *"If I hadn't been in the army I wouldn't have coped half as well as I've done."*

He cites this experience and working as a professional carer as enabling him in his current responsibilities and gained satisfaction from his self-narrative as a good carer. Colin and Deidre had both cared for their mothers in their youth, Colin as a child and Deidre as a teenager. Colin consciously utilised this self-narrative in caring for Carol now.

> *" I'm better suited to this and luckier than most people, because it's familiar."*

He constructed a past family narrative of loyalty, mutual support, resilience and transparency which he has sought to replicate in his family with Carol. Deidre's early family life was challenging and adopting the mantle of family carer supported her self-narrative of resilience; this has served her well throughout her life and particularly as she has cared for Dave, as she put it:

> *"I had to get on with it."*

In surviving a contentious divorce, migrating to England alone and gaining a degree, Estelle has constructed an narrative of strength, independence and resilience which she has drawn upon to manage her current life. Valerie used her interview to review both the narratives of her life and her relationship with Maxim. She emphasised her identity as an adaptable survivor:

> *"So adapting is one of the things I do."*

She attributed her independence and resilience to dealing with a number of early losses yet acknowledged it has been at a cost: she has struggled with depression and alcoholism for much of her life.

In summary, each of the participants was able to draw upon previous self-narratives to manage the period since their partner's terminal diagnosis. For each, however, there have been aspects of this time for which they were unprepared. All had suffered bereavements but none of them had dealt with losing a partner. Colin, Deidre and Brian were all very young when they met their partners and Colin and Deidre have never lived alone and have no template for managing this. All face the challenge of the unknown territory ahead.

Temporality

Illness ruptures our sense of temporal continuity. For those facing a terminal illness and for their partners, the foundation upon which life together has been built is threatened. The expected narrative is interrupted and loses coherence. For the participants, the individual and couple narratives of the period since the terminal prognosis can be understood as attempts to contextualise the illness story into the overall individual and couple narratives.

Because of the time-limited nature of a terminal illness, time can appear to take on different meanings, both for the dying person and for those caring for them. The open-ended narrative becomes time-limited. Timeframes predicted by a GP or hospital consultant often proved inaccurate, partners were still living long after the predicted death. This may be welcome and yet brings its own challenges. It is understandable that dying patients and their families should seek some kind of certainty regarding future narratives: not knowing how much time is left together can leave couples in limbo but inaccurate predictions can be equally unsettling. Uncertainty of timeframes coupled with the certainty of death is a challenge to both partners.

For all of the participants, integrating the end-of-life narrative into the whole life story was critical, a reassessment of past and future narratives. It was most challenging for Estelle. The timing of Evan's illness in the family life-

cycle represented a particularly brutal disruption of the previously expected individual, couple and family narratives. Her story illustrates the challenges of finding meaning and coherence at this time. All the participants were faced with the knowledge that, while their individual narrative would continue into the future, their partner's would not. While the previous couple narratives had been shared and the illness faced together, as *we,* the joint narrative was now coming to an end. For some couples this had been addressed explicitly, for others it remained a hidden narrative.

The experience of the time between receiving a terminal prognosis and death depended on individual and couple narratives and the health of both partners. Two of the participants, Anna and Colin, constructed couple narratives valuing this time. Anna made a decision to live in the moment, rather than worrying about what lay ahead. The fact that it was a *special time* did not preclude the intense experience of grief for either Colin or Anna. For other participants, while there had been enjoyable times together, health issues and uncertainty precluded living these last months to the full.

In periods of such intensity, the quality of time can appear distorted, sometimes stretching, sometimes shrinking. At times it can seem there is too little time, at other times too much. Anna, in her journal, described her current experience of time.

> *"It feels like elastic being stretched and stretched – time that is, but also the not-knowing and the ongoing low grade anxiety."*

In Colin's journal he referred to a sense of time running out but on another occasion a sense of time extending, leaving him with a sense of anticlimax and a somewhat guilty awareness that he does not want the situation to continue indefinitely. The time-limited aspect of a terminal cancer prognosis lends intensity to these last months, sometimes positive, always painful. All the participants, to some degree, were dealing with the disruption of their predicted narrative, the loss of an expected future. Anna had accepted she would outlive Anthony but had not expected it would happen so soon or so

suddenly. Colin had an imagined future narrative of growing old together with Carol but this had been lost to them. Brian and Beth had future plans that would never be fulfilled. Estelle's long-anticipated future narrative of a family life with Evan and the children was cut short. For all the couple narratives, time was running out.

Gender

The narratives of the four women in the study constructed caring for their partner in illness as a natural extension of the caring role they had previously inhabited in the partnership and a good fit with their gendered identity. Two of the women, Anna and Valerie, did not regard themselves as carers, while Deidre and Estelle did. The latter took pride in the expertise they had gained with clinical tasks, adding to their skills and knowledge. Neither of the men in the study, Brian and Colin, regarded caring as gendered and both were reworking traditional narratives of masculinity.

Both men had previous experience as carers and took pride in the expertise they brought to caring for their partners, for each it confirmed their identity as a strong supportive man. Brian had worked as a professional carer and Colin had been a juvenile carer. Both performed their competency and emphasised ease with all aspects of care, finding it neither demeaning nor embarrassing. Colin positioned himself as challenging traditional gender roles.

> *"I was a new man before they were invented"*

Both men constructed themselves as devoted to and protective of their partners, although describing very different relationships. Brian portrayed himself as the wise older man who has always taken care of his younger, less able wife while Colin described a partnership of equals, each partner appreciating the other's qualities. For the first time in their lives both men had relinquished their roles as breadwinners, perhaps another aspect of their

masculine identity. Colin had also given up positions in the community which had brought him respect and confidence as a man.

In both interviews there were performances of masculinity, this perhaps important to each man at a time of vulnerability. Colin took an active role throughout and was gallant towards me, the female interviewer. His self-assurance was balanced by self-deprecating humour. This was also displayed when he described his adult son as taking on the role of the *alpha male* in the family. Colin referred to a family template of masculinity to which he could only aspire. Brian also took an active role in the interview with the performance of identity shown in: *"This is who I am".* He constructed himself as a strong, capable man who had served his country, been successful in a number of work situations and taken good care of his family. Later in the interview he also shared his vulnerability.

All the women described aspects of traditional gender roles in their partnerships, Anna characterising herself and Anthony as:

> *" very gender stereotypical".*

Deidre also described her relationship with her older partner as built upon traditional gender lines, although in her case she had worked throughout their marriage while Dave had not. Deidre had been the carer in her family, particularly since Dave's first cancer diagnosis, and was unsure whether he would have reciprocated if she had needed care.

Valerie described a partnership of equals; constructing a relationship of reciprocal care. She had rejected the template of expected female behaviour offered to her as a young woman. At the same time, Valerie's emotional care and protectiveness of Maxim's masculine identity was apparent. In her journal Valerie indicated her belief that men need to be cared for.

Estelle described her role in supporting Evan and running the home as being culturally informed; women apparently being likely to adopt traditional gender

roles in Madagascar. Like Valerie, she was working to protect Evan's masculine identity. Although employed almost full-time, most of the childcare and home responsibilities fell to Estelle. I was struck by her performance as the good wife and good mother, trying to meet the needs of Evan and her children despite her reported frustration and irritation with her husband. For all the participants, gender was a critical factor in how each constructed themselves as a partner and care provider.

Cultural templates

The participants' cultural backgrounds determined their understanding of care and informed their self-narratives as care providers. All of them viewed caring for their partner as their responsibility, this being informed by family and cultural expectations. Cultural factors affected how the participants and their partners broached conversations regarding illness and care. The cultural differences within the partnerships in this study did not signify noticeable differences in expectations of care.

The current cultural context, in which cancer is widely discussed in the media, is critical in how the participants constructed their partner's illness and their responsibility to care for them. This was reflected in how the participants talked about it. All used the term *cancer* freely and were familiar with some of the medical terminology surrounding it. Some, particularly Estelle, had considered the wider issues concerning family care providers.

There was some cultural diversity in the participant group which included white British, Irish, Anglo-French and Madagascan participants. All of them, irrespective of gender or cultural background, constructed caring for their partner in illness as an accepted part of the couple relationship. As Colin phrased it:

> *"It was the deal".*

It was apparent how the participants' backgrounds had informed their identities as partners and carers. Two of the participants, Deidre and Estelle, were immigrants to Britain and this impacted on how they constructed and experienced caring for their partner. Both were cut off from wider family support when it was most needed. In Deidre's case, her children did not fulfil her cultural expectations of family loyalty. Estelle's strong work ethic may be informed by her background and her status as an immigrant who will soon be left to raise her children alone.

Three of the participants were from a different cultural background from their partner. Estelle and Evan were Madagascan and Welsh; Deidre and Dave, Irish and Scottish and Valerie and Maxim, Anglo-French and Russian. None of them presented difference as either an advantage or disadvantage. Deidre brought her cultural template of family care to the current context and prized family loyalty.

> *"...we* (the sibling group) *had nothing growing up, but we seemed to have each other, and if anything happens, we're there for each other."*

Valerie's mother had provided a role model in flouting cultural expectations by marrying Valerie's French father. Valerie and Maxim had each had several previous partnerships and had forged their couple relationship of mutual respect on their own terms. Although Valerie rejected some of the values of her upbringing, she acknowledged that her relationship to duty and adaptability were informed by her background and Catholic convent education:

> *"You have responsibilities, and if you take on a job, or a responsibility, or whatever it is, you do it to the best of your ability."*

Anna, Colin and Brian and their partners were all white British. All had similar cultural backgrounds to their partner and all shared a similar ethos of family life to their partner. Anna, in common with many women of her age,

constructed caring for her husband and family as her priority. Colin and Carol drew their cultural template of family mainly from Colin's family. This narrative prioritised responsibility, humour and making the most of life and had been helpful over the previous year. Brian's cultural identity was strongly influenced by his years in the army, which he constructed as critical in how he was coping with caring for Beth in her terminal illness.

The participants spanned a broad range in terms of both wealth and educational achievement. Deidre had left school at thirteen and lacked confidence in her education and literacy, this probably deterred her from keeping a journal. Money had been an issue for some of the participants since their partner became ill and they were unable to work. The carer's allowance plus a grant from Macmillan had made a significant difference to both Deidre and Brian and their partners.

Spiritual beliefs

I asked each participant whether spiritual beliefs were important to them. None of them raised the subject spontaneously and this may reflect the level of discussion of beliefs in current social discourse. The participants spanned a broad range of their beliefs including: Hindu, Catholic, Protestant and no specific belief. For some, religion was central to their lives, for most it was not. Some participants shared religious beliefs with their partner and for those who held different beliefs there was a mutual respect for the other's religion or lack thereof.

Some participants described the importance to them of the church as a cultural institution. Colin and Carol had strong links to their local church and this had been an important resource socially and spiritually. For this couple their shared believe was an important aspect of the couple narrative. For Anna, the church was important in marking family rituals and milestones, sustaining the narrative of continuing family life over time.

For Estelle and Evan, religion had become more important since Evan's terminal diagnosis. Although raised as a Hindu, Estelle had received a Catholic education and was familiar with Catholicism. She had supported Evan on a trip to Lourdes, which both partners had experienced as beneficial.

Deidre and Valerie had both been raised as Catholics although neither were practicing now. Valerie was aware of how Catholicism had informed her self-narrative, both in values embraced and values rejected. Deidre demonstrated pragmatism in her multiple positions on religion; she concealed the fact that Dave was a Protestant from her family to avoid conflict and had her children christened as Catholic without Dave's knowledge or consent. She did not attend church and was unsure of her beliefs but did pray occasionally. Brian also adopted multiple positions; he was not a believer although, when in dangerous situations in the army, he had kept a bible in his pocket and occasionally prayed. He also made reference to "*him upstairs"* when referring to Beth's death.

Several of the participants described a belief in life after death and for those who did the idea brought comfort. Colin stated:

> *"We both believe there's something else, quite what… there's something else, and that helps".*

Valerie also believed there must be something beyond death. She was unsure what form this might take but viewed it positively:

> *"It's the next great adventure, as I see it."*

This belief was not shared by her partner, Maxim. Brian, Anna, Deidre and their partners did not believe in everlasting life. I did not explore Estelle's beliefs regarding life after death or reincarnation, although, as a Hindu, these may have been important for her.

The participants held a range of beliefs about religion and life after death. Brian's and Deidre's narratives illustrate the nuances of believing /not believing. Differences in religion within couples had been accommodated. There was no correlation between religious belief and belief in everlasting life, but for those who believed there was *something else* the idea brought solace: the possibility of a continuing narrative

The couple relationship narratives

Participants used the time since the terminal prognosis to sustain and reconstruct their couple relationship narratives. Narratives of the past relationship were reworked and re-valued in the light of the terminal prognosis. In this section I will examine various aspects of the couple relationship narratives including: valuing and sustaining the couple relationship narrative, rebalancing the couple narrative and narratives of facing illness together

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Valuing and sustaining the couple relationship narrative

In the face of a terminal prognosis participants worked to reconstruct positive narratives of the past and present couple relationships, sustaining valued relational narratives and reconstructing others.

Most participants gave accounts of working to preserve the previous couple narrative by prioritising the enjoyable activities that were still possible. Colin and Carol purposefully did as much together as possible; the knowledge that time was limited adding poignancy to shared activities. Food took on particular significance in several participants' narratives, particularly Deidre's and Valerie's. It became a marker of their partner's health over time, an expression of love and care and a continuation of the rituals of the couple's life. These day-by-day events, *small stories,* served to remind a couple of who they are and what they have been to each other and perhaps created narratives to be treasured in the future. Two of the participants commented upon how the time

since receiving the terminal prognosis had been the happiest period in the couple's life together.

Anna: *"It's been amazing….the best time ever."*

Colin: *"It has been one of the happiest times of our life."*

The knowledge that time was limited lent intensity and poignancy to this period. In making the most of the remaining time together participants constructed positive memories, a potential resource in the future.

All the participants had used the knowledge that their time together was limited to review their relationship over time. For some, particularly Colin and Anna, the narrative of the past relationship was co-constructed with their partner, revisiting and revaluing a shared life; for others the interview provided the opportunity for reviewing and reworking the couple narrative. All of the participants appeared to gain satisfaction from revisiting earlier couple narratives. Valerie remembered meeting Maxim and his falling for her and Estelle spoke warmly of her early relationship with Evan. In Colin's journal he reflected on his early days with Carol in describing:

> *"A love affair which has lasted 46 years".*

Deidre, candid in her overall assessment of her relationship with Dave, enjoyed revisiting the story of their meeting. For all the participants, sustaining the romance of early relationship narratives had particular significance now that time was limited and was a way of preserving and adding value to the couple narrative.

Some accounts reflected the cultural couple narrative of closeness through surviving adversity: couple narratives of resilience. Brian indicated that the difficulties he and Beth have endured throughout their life have strengthened their bond.

"... we've been through some rubbish in our lives but we've always worked our way through it."

Beth's illness had also enhanced closeness. Valerie and Maxim had survived many challenges in their life together, contributing to the closeness which Valerie described. Their current relationship was a continuation of the close, reciprocal bond previously enjoyed. Deidre, who expressed her feelings for Dave more in actions than words, reported showing more compassion and consideration towards him than previously.

Rebalancing the couple narrative

Several participants gave an account of a shift in the balance of power in the couple relationship, sometimes initiated by the increased dependency of the ill partner. Deidre's narrative indicated a previous rebalancing of the couple narrative in response to marital difficulties and Dave's previous illness. His current illness and Deidre's competency further strengthened her position. Anna noted that, for the first time in a long marriage, she was certain that Anthony needed her as much as she needed him. Anna and Deidre and their partners were able to accommodate the change of balance necessitated by the partners increasing dependence while sustaining the couple narrative. Brian described a recent change in the balance of his couple relationship which, at the time of the interview, was still being assimilated into the couple narrative. His account illustrated a shift prompted by Beth taking the initiative for discussing whether to continue chemotherapy and Brian adopting a supportive position.

Changes in the balance of the couple relationship can also be challenging. Estelle adopted multiple positions in the balance of power in her relationship with Evan; she felt she had to become stronger herself to deal with increased responsibilities and still wanted to bolster Evan's identity as the man of the family. Sustaining the relational narrative in the face of his progressive illness was difficult and Estelle described increased friction between them.

Other participants, Valerie and Colin, portrayed couple relational narratives of equality both before and since the terminal prognosis. Valerie's account illustrated how she worked to sustain this balance by ensuring that Maxim was supported in his masculine identity when he had few opportunities to perform it.

Narratives of facing illness together

All the participants constructed themselves as joint partners in the face of the terminal illness. All described facing the illness conjointly, as ***we***. This is illustrated in the frequent use of ***we*** in the participant's accounts. The following examples are from Brian's and Colin's narratives.

> *"**We** can't keep going along with our doctor's decision, **we'll** have a second opinion."*
> *"But then in a short space of time **we** went from category 1 to category 3".*
>
> *"...and then **we** got the terminal prognosis…"*

In the first example Brian constructs himself as an active agent in accessing appropriate treatment for Beth and in the second he characterises the disease as being experienced conjointly. In the third example Colin constructs the terminal prognosis as being jointly experienced. In these examples, as in most of the narratives, the language illustrates how couple narratives of standing together against adversity are utilised. In supporting their partner as the illness progresses, participants are sustaining (and perhaps building upon) relational narratives of care and reinforcing couple narratives of resilience.

For both partners joint involvement can be beneficial. Ill partners were supported at their most vulnerable and, for participants, active involvement increased their sense of agency at a time when they were feeling helpless, thus supporting self-narratives of fortitude. The sense of being valued by the

clinical team was important to some participants, a further boost to positive self-narratives.

Each couple's illness narrative varied with the progression of the disease. In the earlier stages of diagnosis and treatment most of the participants described the *performance of we* facing illness together and communicating openly about the diagnosis and treatment. In the later stages, while still facing the illness together, addressing problems conjointly became more challenging for some participants. Couple narratives of transparency were harder to sustain as the partner's death drew closer and they sought to protect their partner from distress. Facing illness together was helpful to both partners but, in a terminal illness, is coupled with the knowledge that future narratives will not be shared.

Summary of the couple relationship narratives

In the period since the terminal prognosis participants had reconstructed past and present couple narratives. Past narratives had been reviewed and re-valued, sometimes co-constructed with the partner, in the light of the terminal prognosis. The time since prognosis was used to sustain previous couple narratives and, within the constraints of the illness, create positive narratives for the future.

Most participants portrayed a re-balancing of the couple narrative to accommodate changes in their partners health, more challenging for some couples than others. There was a common couple narrative of closeness through adversity; for some the experience of illness had enhanced the couple bond. Several of the participants were working to sustain the couple narrative by supporting their partner's previous role in the relationship. All the participants were facing the illness as joint partners and this had been positive for self and couple narratives.

All of the participants in this study gave accounts of strong, enduring couple relationships. The dominant themes of most narratives were love, mutual

support and sadness at what will be lost. It could be argued that people experiencing more difficulty in their relationships or who were not coping well with the challenges of caring for a partner would be less likely to volunteer to talk about their lives at this time.

The narrative typology

A narrative typology can be defined as a categorisation of narrative types selected to represent a particular group of narratives, for example illness narratives. In this study the purpose of the typology is to highlight archetypal storylines across the narratives of people caring for a partner at the end of life. I have identified three narrative types. The *blow-by-blow* narratives show how participants sought to construct coherence and meaning in the illness story and *champion* and *resilience* narratives demonstrate how participants utilised positive self and relational narratives to manage a time of biographical disruption. The types selected are not intended to encompass all aspects of a particular story. Each case example may include all the narrative types and there is inevitably overlap between the categories.

Blow-by-blow narratives

I started each interview with an open question, such as:

> *"How did you first realise (your partner) was ill?*

In most of the interviews this elicited a prolonged and detailed account of the illness journey, from the first symptoms up to the present time, including diagnosis, investigations and treatments. The narratives provided a glimpse into the relentless and accumulative progress of the illnesses and the impact upon both partners. Initial hopes of recovery and remission fade as

uncertainty is followed by bad news in a repeating cycle, described by Brian as a "*roller-coaster*".

Each participant was viewing the progress of the illness through the lens of the present, the current terminal prognosis. This is congruent with the *teleogenic plot*; defined by Davis (1987), and quoted in Paley (2009), as a narrative which from the outset is shaped by the narrator's awareness of the ending. Each stage of the partner's illness took on a particular significance in retrospect. Symptoms, such as Anthony's cough, Beth's breast lump, Dave's loss of balance and Evan's headaches, initially disregarded by either the couple or clinicians, become critical to the illness narrative. Instances when clinicians did not initiate investigations despite repeated requests were recalled with particular clarity when, as perceived by the participant, the subsequent diagnosis validated the request. These instances are of particular poignancy when there is a suggestion of negligence or a regret that there could or should have been a different outcome, narratives of *if only* within the narrative as a whole.

Most of the interviewees were keen to tell the story of the illness and there seemed to be a pressure to portray it accurately, to emphasise the physical impact of the disease on their partner and the couple narrative. These accounts were detailed and chronological. Their construction adds authenticity to the account. They work to provide evidence of what the ill partner and the couple have endured since the first signs of illness. These accounts were attempts to find order and meaning in what had been a chaotic and overwhelming experience for the couple and for the individual.

The blow-by-blow narratives have the purpose of restoring the disruptive damage caused by the terminal illness, as observed by Frank (1995) and Hydén (1997) in describing illness narratives. Some participants related detailed illness narratives using direct speech; bringing to life the intensity of the illness journey and engaging the listener in the story. The participant's role in the narrative was emphasised. An example of a *blow-by-blow* narrative can be found in Appendix X.

The accounts of the partners' illness and treatments illustrated the participants' complex relationships with the medical system. There was often an implied acceptance of the medical narrative of disease, illustrated in the frequent use of medical terminology and abbreviations. This spoke to the participants' growing expertise in medical knowledge. At the same time there were attempts to reclaim the narrative as a personal story, something being experienced by the individual, the couple and the family. A difference was apparent in the accounts of interventions by surgeons and other clinicians earlier in the progression of the illness in contrast to the narratives of palliative care.

Although reworked and performed in the interview, it is likely that these blow-by-blow narratives had been co-constructed with the partner. They had probably been rehearsed and amended over time and many tellings with the partner, family, close friends and perhaps clinicians. These narratives work to give meaning and coherence to an experience over which the participant had little control. They highlight the pivotal role of each participant in the partner's illness journey, bringing forth a sense of agency.

The champion narratives

To some extent all of the narratives in this study are champion narratives. They are relational narratives which tell of defending a partner and standing up for their needs, rights or wishes when the partner is less able to do so for themselves, performing the identity of champion. In so doing, participants are sustaining and reinforcing their relational narrative as a supportive and protective partner and supporting self-narratives of strength, resilience and justice.

Most of the participants gave examples of constructing the care or treatment offered to their partner as inadequate on some occasions. These examples included: GP surgeries, hospital departments and benefit offices. In each

instance the participant felt compelled to take a stand, prompted by loyalty and care for their partner and a sense of justice.

Each participant drew upon previous self-narratives of strength to perform the identity of champion. Deidre drew on her self-narrative of stoicism and her sense of justice to access treatment for Dave. In narrating her story she became stronger, inhabiting the identity of the champion. Brian drew on his self-narrative as an effective, competent man and his relational narrative as Beth's protector to become her champion. Anna's and Valerie's narratives as champions were informed by a sense of justice and relational narratives as devoted and protective partners.

Participants gained satisfaction from becoming their partner's advocate and champion. However powerless they were against the illness, each reclaimed some narrative strength through standing up for their partner at a time when their partner was less able to stand up for themselves. In so doing they were reinforcing self-narratives of effectiveness and relational narratives of care. These are also actions and narratives which are constructed for the future. As Anna put it:

"I don't want to ever look back on this time with any regrets, ***ever****."*

Most of the participants were critical of some aspects of the healthcare their partner had received (although notably not the hospices) and it is possible that the care offered was inadequate. Watching a partner's condition deteriorate can lead to feelings of helplessness and frustration and participants constructed narratives to find meaning in the situation. Becoming the partner's champion within the system allowed alternatives to the dominant medical narrative of privileged knowledge to emerge; power was reclaimed on behalf of the ill partner.

The resilience narratives

These narratives highlight how participants drew on both personal and couple narratives of resilience to manage the period since the terminal prognosis. I examine how these narratives inform the strategies used to endure the difficulties of this period and how these reciprocally reinforce personal narratives of strength.

All the participants gave accounts of facing and overcoming difficulties in the past. Although none had previously been widowed, all had experienced previous bereavements. All had lost one or both parents, some, like Anna and Estelle, fairly recently. Valerie constructed having experienced multiple bereavements in the past as helpful in facing the loss of Maxim.

> *"I'll be bereft, of course, but, it will pass. Because I know that, it will probably pass more quickly than it would for someone else."*

Self-narratives of having survived loss could be drawn upon by all the participants. Valerie and Anna had both faced challenges in their own health. Valerie, who had a history of alcoholism and depression and was in very poor health, downplayed this narrative of disadvantage to focus on caring for Maxim. Anna drew on a narrative of overcoming past health difficulty to increase her resolve to remain strong.

> *"I won't have a breakdown, I've had them in the past, [...] it's not going to happen again. I'm not telling myself that, I know it's not."*

Deidre and Colin both drew on narratives of caring for a parent in their youth to construct self-narratives of resilience. Deidre had adopted the mantle of stoicism in a family where others were less robust, while Colin's self-narrative was also informed by his parent's template for surviving adversity, which had helped them to optimise family life despite his mother's quadriplegia.

> *"Take the hand that fate dealt you and play it for all it's worth"*

Valerie and Estelle had both survived contentious divorces, and in Valerie's case several relationship breakdowns. While Valerie acknowledged the negative impact of these events, she also attributed her self-narrative of transparency to this, a source of strength for her now. Estelle moving alone to England and gaining a degree after her divorce was constructed as a narrative of strength. Her relational narrative as a mother supported her self-narrative of resilience.

Participants' positive self-narratives reinforced the construction of narratives of resilience. Colin drew on his self-narrative as an amusing, competent man and Brian used his self-narrative as a resolute and forthright coper. Valerie drew on her self-narrative as an adaptable survivor while Estelle and Deidre both portrayed pragmatism. Anna drew on a self-narrative of independence. Several participants drew on professional identities to reinforce narratives of resilience. Brian referred to his army experience while Colin spoke of his voluntary work and management training. Anna's professional identity informed her insight while Valerie constructed her previous careers as a source of pride.

Self-narratives of resilience informed the development of strategies for managing the period since the terminal prognosis. A number of participants, most notably Colin, made comparisons between their ability to cope and that of others in similar situations. In so doing they constructed themselves as both fortunate and capable, this supporting self-narratives of strength. Acquiring the practical skills of caring including giving medication and, in Deidre's case, performing minor clinical procedures, also contributed to personal narratives of resilience and pride. For all participants, constructing themselves as caring for their partner as best they could supported positive relational narratives.

Other strategies were used by participants. Anna used personal writing to process the impact of the prognosis and she resolved to *live in the day* rather than worrying about the future. Estelle used her work as a survival strategy: sustaining her identity outside of her roles as mother, wife and carer

contributed to her positive self-narrative. She also used the acquisition of knowledge about Evan's condition and treatment to increase her sense of agency.

Most participants portrayed couple narratives of resilience. Some couples had become closer as a result of adversity. Brian suggested that he and Beth had gained strength as a couple from the difficulties they had survived together. Deidre and Dave had overcome difficulties earlier in their relationship to remain together. Valerie and Maxim had endured considerable adversity including alcoholism, bankruptcy and ill-health, sustaining a couple narrative of loyalty and resilience. All couples had used survival strategies to manage the period since prognosis. Most focused on short term hope, not of recovery but of enjoying whatever time they had left. These experiences sustained and strengthened couple narratives of companionship and resilience while constructing positive narratives to be valued by participants in the future.

Summary of the typology

The typology represents narrative types which were prominent in the narratives but does nor represent all aspects of the participants' stories. The *blow-by-blow* narratives highlighted the accumulative impact of the progression of a terminal illness on both partners as constructed by the participant. The *resilience* and *champion* narratives represent important aspects of participants' identities. They could be characterised as privileged narratives, those that participants found easiest to share with the world and perhaps those that the world and the participants wanted to hear. For each participant there were also less privileged narratives: private pain, a sense of loss and fears for the future. These are represented in the analysis of narrative themes and discussed in the following chapter.

The Journals

The content of the journals was analysed with interviews in the individual analyses and cross-narrative analysis. In this section I will consider how participants approached keeping a journal and how the journals contributed to the study.

All of the participants were invited to write a journal but it was made clear that there was no obligation to do so. None of the participants refused outright but Brian and Deidre were doubtful from the outset. Estelle expressed interest in keeping a journal but in the event did not do so because of time constraints. Of the three participants who did write one, Anna and Valerie wrote a paper journal and Colin wrote his by email.

Anna, Valerie and Colin all expressed considerable interest in keeping a journal. For Anna the journal proved very different from the writing she had done following Anthony's terminal prognosis: the *public written-self* as opposed to the *private written-self*. She reported that writing spontaneously for herself had been very helpful in processing the unexpected news. In contrast, writing a journal at my suggestion proved inhibiting, at least partly due to the fact that it would be read and analysed by others. This fitted with Anna's sense that her grief was too private to be shared.

In contrast, both Colin and Valerie approached their journal with enthusiasm and made it their own. Both appeared to gain relief from writing. Valerie used her journal to process a tumultuous period, close to Maxim's death. The fact that she was hospitalised yet continued writing suggests that she gained some benefit from expressing herself on paper. The written-selves constructed by both Anna and Valerie were not dissimilar to the identities performed in their interviews. Although less eloquent than her presentation as an interviewee Anna's journal provided a valuable account of her day-by-day care, vigilance and focus on Anthony. Valerie's journal was determined by the context, her overriding preoccupation is to be reunited with Maxim so that he

could die in peace at home. Her written-self, as in the interview, was animated, perhaps informed by the intensity of the situation.

Colin used his journal to give voice to his less privileged narratives of loss and fear, not expressed in the interview. His written-self suggested a thoughtfully constructed self, indicated by the language used. There are also passages showing the positivity and humour performed in the interview. Both Colin and Anna demonstrated self-reflexivity in their journals, observing passing thoughts and commenting upon them. Both Colin and Valerie decided to continue with their journals after the study, an indication of the benefit gained.

The three journals were very different from each other but, for each participant, the *written-self* represented a notable addition to the overall narrative. Although the journals were originally suggested by me, the material was produced spontaneously in response to the participants' daily life and relationships. Reflections, both positive and negative, were captured and further considered. The potential therapeutic benefit of journals for people caring for a terminally ill partner is highlighted.

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In this chapter I have presented my analysis across the narratives, using both an analysis of narrative themes and a typology. The journals were reviewed together. In the following chapter I will discuss the findings of the study and relate them to the literature.

Chapter 7

Discussion

Introduction

In this chapter I discuss the findings of the study and link them to the literature. I consider the strengths and limitations of this study and evaluate the quality based upon accepted guidelines (Elliott et al, 1999; Potter and Hepburn, 2005). I review the self-reflexivity issues which arose over the course of the study and discuss the clinical implications of the study. This is followed by the conclusion.

Summary of findings

This study provides a detailed snapshot of the lives, relationships and identities of people caring for a partner with terminal cancer. A narrative analysis has enabled a detailed exploration of how personal and couple narratives are employed and constructed by participants in the period following their partner's terminal prognosis. All the participants constructed themselves as joint partners on the illness journey. The terminal prognosis is represented as a disruption to expected individual and couple narratives; the imagined future as a couple had been cut short. The most notable findings are as follows. In the period since the partner's terminal prognosis, participants had worked to sustain, reconstruct and co-construct self and couple narratives in order to give meaning and coherence to their lives. The study highlights the complex issues concerning spoken and unspoken narratives and how these relate to individual identity and couple relationships. I have identified a typology of narratives utilised by participants. The *blow-by-blow* accounts were used to construct coherence and meaning in the illness story, while *champion* and *resilience* narratives construct identities which sustained a positive sense of self in the face of impending loss.

The ethics of telling, listening and interpretation: What is a *good story?*

The participants in this study were a self-selected group and all gave a *good account of themselves,* in terms of being good storytellers, narrating coherent, vibrant accounts of their lives and relationships, and in their depiction of themselves as good partners and good care providers. Wren (2012) argues that narrative accounts are always normative, always based upon value judgements of ourselves and others. A complicating factor in care providers' narratives may be the noble image of *the carer* in current discourse, which could be experienced as either inspiring or burdensome (Stajduhar and Cohen, 2009). Wren observes the tension for clinician-researchers listening to and interpreting narratives. This tension is between evaluations, which are based upon the widely accepted tenets of good stories, and privileging the ethical logic of the teller. She highlights the importance of reflexivity in examining one's own moral positions and in one's accountability to those of the participants. In this study the moral positioning of the participants was particularly apparent. Their narratives all constructed the participants as working to do what was right for their partner at the end of their life.

Frank (1995) suggests that what makes for a *good story* is a story's narrative truth and the act of *witness,* referring to an individual's ability to bear witness to their own suffering. Wren (2012) critiques our understanding of what constitutes a good story. Clinicians may regard qualities such as authenticity, self-awareness, consistency and concern for others as desirable in an account, while clinician-researchers may value qualities such as acknowledgement of complexity or uncertainty, hopefulness, self-reflexivity and a willingness to take responsibility for action. Riessman (2008) considers the problem of establishing the validity of stories and the place of coherence and internal consistency within it. The rhetorical devices employed by the participants in this study reinforce their validity. The *blow-by-blow* narratives illustrate how participants worked to establish consistency and coherence by chronological ordering and linking of events over time.

Considering the narratives in this study in the light of these ideas, I would add the following observations. I accepted the validity of the accounts as the participants' narrative truth. I was impressed by the richness, variety and coherence of the narratives and by the participants' openness. I considered them all *good stories*. Although appreciative of the participants' fluency, some of the most compelling parts of the narratives for me were paradoxically in the less coherent, stumbling parts of the accounts, perhaps when less rehearsed, less privileged stories were being articulated. I was aware that the participants (in common with us all) would prefer to present themselves in some ways rather than others. I experienced the tension of representing these preferred performances of self, for example the *wise, protective partner* or the *adaptable survivor* as opposed to the less privileged narratives of sadness or fear. I was aware that not only were participants performing their preferred versions of themselves, they may also be privileging the self they believed I would like to interview, also discussed by Wren (2012).

Frank (2010) highlights a potential danger of stories when the idea of overcoming adversity is embedded within the narrative. This could be applied to c*hampion* and *resilience* stories. I recognise the danger of these *heroic* stories becoming the preferred narrative, either for the participant, myself as researcher or even the reader and have included other less frequently articulated narratives of fear and loss. Frank also describes the danger of stories becoming insular, one narrative reinforcing the next in an iterative way. This point underlined to me the importance of being open to alternative stories, to value each narrative on its own terms and to avoid the temptation to fit narratives into an existing frame: in Frank's words, to finalise them.

Canonical narratives

There may be considerable normative family or cultural pressure to take on the terminal care of a family member (Stajduhar and Cohen, 2009). Within a couple relationship there is often a particular sense of obligation to care for a partner who is ill or dying, irrespective of the previous relationship. Although

marriage vows in the UK today do not always include the words *in sickness and in health,* there is an expectation of reciprocal care. This was reflected in Colin's comment, *"It's the deal".* While the participants in this study generally recounted giving their time and care willingly, there was also a sense that it was understood as their responsibility.

Most people would prefer to die at home rather than in hospital or a hospice, although only 18% do so (Gomes and Higginson, 2008, 2012). There is a growing acceptance that this is often the best option (Gawande 2014). It is, however, also contingent upon partners or family members being willing and able to offer their time and effort. For many, including the participants in this study, this will be the first experience of caring for someone who is dying but, in the context of a partner's wishes combined with current ideas of *a good death,* it could be hard to demur. This point is emphasised by Kellehear (2009) and Stajduhar and Cohen (2009). Most of the participants in this study actively wanted their partner to die at home and to provide the care themselves.

Cultural Templates

Participants' construction of their partner's terminal illness, their position within the illness system and how this impacted upon the ongoing couple relationship was informed by the interweaving of canonical discourses, cultural templates, family scripts and previous narratives of illness, care and couple relationships. All participants, whether white British or from another culture, drew upon cultural templates of care and loyalty towards a partner who was unwell, perhaps reflecting universal couple narratives. As Forbat (2005) observed, caring is constructed as an unremarkable component of family life in most cultures.

For some participants there was dissonance between previous cultural templates for managing difficulty and what the current situation required. One participant who had prided himself on his independence and protective stance towards his wife reassessed his position to accommodate changes in how she

now constructed and responded to her illness. For another participant her cultural template of filial care and responsibility was challenged by her perception of her children's lack of support over the period of her husband's terminal illness. This was in contrast to another participant who took pride in how the family template of loyalty and care had been replicated in the next generation. The two participants who were immigrants, from Ireland and Madagascar, did not have access to the wider family support available to some other participants (Altschuler, 2013). Another participant's relocation and life changes had similarly left her with limited social support. All of these participants particularly valued telephone contact with a sibling, an alternative narrative of family loyalty in the absence of physical contact.

Cultural templates also informed how participants constructed their couple narratives. All of the female participants and one of the men referred to gendered discourses in their relational narratives; whether in protecting their partner's masculine identity or in expectations of their partner's behaviour or abilities. Some participants had sought to replicate family templates of being a couple while another had resolved, not entirely successfully, to construct a different couple narrative from her parents.

Participants' constructions of illness and death and how they could be talked about were also informed by their cultural templates. Although all were explicit in naming partners' illnesses as cancer, there was variation in how freely participants could discuss the implications with their partners and others. There was also variation in how participants sought or could accept help from professionals, friends and family. Some participants preferred to provide as much care at home themselves as possible while for others a more open acceptance of outside help was apparent. This could have been attributable to family templates of privacy and self-sufficiency in addition to any cultural factors. Overall, there was less variation between how participants from different cultures constructed their experiences and identity than I had anticipated. Siefert et al (2008), in a comparative study of cancer caregivers from different ethnicities, similarly found no differences between cultural groups. The authors suggest that the experience of caregiving may

create its own cultural identity. This could have been the case for the participants in this study.

Resisting / adopting a *carer* identity

Three of the participants described themselves as carers and three did not; this did not determine how other aspects of the couple relationship was constructed. Those who self-identified as carers took pride in the skill and professionalism they had acquired. This identity could be compared to the *co-worker* carer position identified in Twigg and Atkin's (1994) typology or the *professional informal carer,* as described by Forbat (2005). Participants who had previous experience of providing care, personal or professional, drew on these self-narratives to construct themselves as competent, experienced care providers to their partner. This concurs with Forbat (2005), who states that previous experience as a carer can give credence to a current account of care and *history talk* can help the construction of identity as a carer.

Those who rejected the label of carer constructed caring for their partner as a natural extension of the reciprocal care in the relationship, thus sustaining previous personal and couple narratives. This narrative emphasises that care was given freely and willingly, out of love rather than obligation. It may be that, in rejecting the identity of *carer,* participants were protecting their partner from the identity of *patient.* Altschuler (2012) and Frank (2010) highlight the danger of identity becoming subsumed by illness. Similarly, there can be a danger of identity becoming subsumed by the identity of the care provider role. In this study most participants worked to sustain personal and relational narratives outside those of care provider. Forbat (2005) examines the meaning of the terms *carer, cared-for* and *care-recipient* in the care relationship and suggests they can imply static identities and unidirectional care and dependency, in contrast to the reciprocity described by several participants in this study.

All of the participants gave accounts of providing high quality care to their partner, prioritising their partner's needs over other responsibilities and

personal needs. Performing competency and skill reinforced self-narratives of resilience. Stajduhar and Cohen (2009), Wong et al (2009) and Ussher et al (2013) emphasise the potential benefits and satisfaction from adopting caring roles. Participants drew on self-narratives of justice, loyalty and compassion to provide sensitive care even when feeling tired or irritated with their partner. Each participant to some extent constructed themselves as a good care provider and the *champion* and *resilience* narratives both support this identity. It is perhaps understandable that these should be the privileged narratives for participants in this position. Those who volunteered to participate or were selected by recruiters (*gate-keeping,* as described by Hudson and Payne, 2009) may have been those most likely to give a good account of themselves.

Individual and Couple Identity

For all the participants their partner's terminal prognosis had impacted on them in multiple ways. Self-narratives, relational narratives and couple narratives had been profoundly affected by the impending loss. This was illustrated by the comparison some participants made with *losing a limb.* All the couples in the study had been together for a long time, some for their entire adult lives. Participants had co-constructed their individual and couple identities with their partner. All the participants had, to some extent, been defined by others and themselves as a partner. These relational self-narratives, built up over many years, have informed how they relate to their partner and to the world. The relational identity provided the sense of being loved, of being the most important person to another, and this was brought to increased awareness by the prognosis. Mishler (1986), describing the *dialogic* self, argues that the self is continually constructed through narrative. The participants self, relational and couple narratives had been altered to accommodate the future narrative of loss.

The participants all constructed themselves as joint partners in the illness journey, illustrated in the *blow-by-blow* narratives. All had been fully involved from the first diagnosis onwards, constructing the disease, prognosis and

treatments as being experienced by both partners. This was highlighted by the frequent use of the pronoun *"we".* Adopting this stance provided support for the ill partner and reinforced participants' self-narratives as caring partners. Participants accounts suggest this brought them satisfaction. Skerrett (2003), Kayser et al (2007), Hubbard et al (2012), Traa et al (2015) and Altschuler (2015) have described this behaviour in couples facing cancer or serious illness as *dyadic coping* and highlight how couples may face the illness conjointly. Most studies suggest dyadic coping has positive implications for couples. This finding is supported by the accounts in this study.

Weingarten (2013) reminds us that while couples may face illness conjointly, they may not share the same experience at the same time. This was the case for some of the couples in the study. The shared experience is also connected to how much a couple have been able to talk to each other, illustrated in *spoken and unspoken narratives*. Without dialogue each partner may make assumptions about the other's experience. Altschuler (2015) discusses how a terminal prognosis creates a disjuncture between expected and lived experience for both the ill person and their partner. For each, the illness represents a biographical disruption but, as Weingarten concludes, the couple must make sense of the knowledge that one of them will survive and the other will not. This was highlighted in one participant's journal.

Couple relationship narratives

The accounts of couple relationships in this study were more positive than those sometimes represented in the literature. This could partly be because, unlike some reports of couple relationships at the end of life, the couples in this study had neither identified nor sought help with problems in their relationships. People experiencing difficulty in their couple relationship would perhaps be less likely to volunteer for a study such as this. Participants may choose to represent the more positive aspects of their couple relationships when their partner is dying.

Some participants constructed the period since receiving a terminal prognosis as being a particularly positive period in the couple relationship, several of the couple narratives portrayed a period of heightened intimacy, drawing on a cultural narrative of closeness and strength in adversity. Altschuler (2012) and Weingarten (2013) note that couples may become closer at this time and Rolland (1994) describes positive changes in couples facing serious illness. Some couples in the study reported a change in the balance of the couple relationship, with the caring partner becoming stronger; this again is supported by the literature (Rolland, 1994; Altschuler, 2015). Only one participant explicitly described increased friction in the relationship and spoke of anger, resentment, guilt and exhaustion. All of these are emotions identified by Rolland (2004) as being an expected part of anticipatory loss. Other participants described occasionally feeling irritation with their partner but trying to curb it. It can be difficult to express negative emotions towards someone who is dying.

Participants in the study were, implicitly or explicitly, working to sustain previous couple narratives in the face of the terminal illness. Some worked to preserve their partner's previous role in the relationship, for example by consulting their partner over decision-making or by supporting their partner's perception of them as contented. Others consciously worked to maintain their partner's level of physical or intellectual activity, thus avoiding a totalising identity as an ill person. In maintaining their partner's previous identity they were sustaining their couple narrative and their own relational narrative. Couples gave accounts of working to preserve and reconstruct narratives of intimacy in the face of the physical challenges of the disease.

Several participants reported prioritising enjoyable shared activities. This worked to sustain and reinforce couple narratives and constructed narratives as a resource for the future. Rolland (2004) notes how families may have particular appreciation of routine daily events when threatened with loss; the rituals / small stories of everyday life (Riessman, 2014) take on extra significance when time is limited. Participants also reconstructed the narratives of romance of their early days with their partner, preserving and

valuing the earlier couple narrative. What is shared with and withheld from a partner can also work to preserve previous couple narratives. *Speaking* sustains couple narratives of closeness and transparency and *not speaking* of fears and sadness can sustain both individual and couple narratives.

Overall, participants in this study constructed very positive couple narratives. The participant who gave an account of increased friction in her couple relationship was a parent of young children and was therefore facing a particularly challenging disruption to her expected future narrative.

Narratives as life review: contextualising illness

My research invited participants to reflect upon their lives and relationships, particularly since their partner's terminal prognosis; all had already begun this process in some way. The knowledge that the remaining time with their partner was limited prompted reflection, as a couple and as individuals. This study identified participants contextualising the illness narrative within overall personal and couple narratives; this is discussed by Hydén (1997). Narratives are used for negotiating the meaning of illness and how we relate to it, of particular importance for both partners at the end of their life together.

Some participants had already spent time, with and without partners, looking back over their lives in order to evaluate and value their individual lives and couple relationships. All drew upon their previous self and couple narratives to negotiate and to find meaning and coherence in their current situation. As Fredman (1997) also observes, families facing terminal illness may usefully review life together even when it has not been possible to discuss dying. Participants in this study used narrative to find meaning in their current situation and also to reflect on past experiences and relationships through the lens of the present. This task of narrative construction is particularly significant to those facing a terminal illness and to their partners. Pals (2006) examines how difficult life experiences may challenge the narrative construction of identity and concludes that positive reconstruction is possible through

narrative. McAdams (2001) also emphasises the importance of life stories in the evolving construction of identity. Although all participants used the interview or journal to review their lives, this was particularly evident in the older participants.

Most of the participants constructed narratives of enduring love in the context of a major life disruption. Although some acknowledged past or present relationship difficulties, the dominant themes were devotion, mutuality and care. The knowledge that time together was limited had prompted most participants to value the overall couple relationship and to foreground memories of the good times. To focus on more challenging aspects of the relationships as their partner was dying could have been constructed as disloyal and could have disrupted relational narratives at a time when it was important to preserve them. Belief in the quality of the relationship sustained relational and personal narratives both at the time and for the future.

Participants found reviewing their lives together to be a positive experience. It was enjoyable for the couple and was important in valuing and reworking relational and couple narratives for the present and the future. A number of authors have highlighted the potential benefits of life review, including: Butler (1963, 2002), Bohlmeijer et al (2003), Peck (2001) and Chochinov, Kristjanson, Breitbart, McClement, Hack, Hassard and Harlos (2011).

For some couples in the study the period since the terminal prognosis had been a time of heightened intensity and closeness and an opportunity to value the couple narrative over time. Memories constructed in this period can become a valuable resource for the participant's future alone. Life review helped in the process of contextualising the terminal illness into the individual and couple life narratives.

Spoken and unspoken narratives

The participants' accounts indicated there was considerable variation between the couples regarding what could be discussed and when. Most described avoiding discussion of topics which they believed could be difficult for their partners. For some participants any discussion of end-of-life issues was difficult, for others practicalities had been discussed but the participant's emotional reaction to their anticipated loss had not been shared with the partner. Participants were consciously protecting their partners, and sometimes themselves, by their silence. In so doing they were sustaining their partner's relational narrative of them as coping well and their personal relational narratives as caring and protective of the partner.

It was apparent in the study that people can simultaneously hold multiple positions regarding what should or should not be talked about and these can appear contradictory, an issue also discussed by Fredman (1997). Three of the participants made a point of emphasising their belief in openness and transparency while all protected their partner from the full extent of the sadness they were experiencing in contemplating their anticipated loss. Speaking openly preserved self and couple narratives of closeness and transparency and remaining silent worked to sustain the partner's narrative of the participant as resilient and positive. By not acknowledging distress openly participants can also sustain narratives of hope. For some, less privileged narratives of sadness found expression in writing while others sought privacy to express grief. Difficult conversations had sometimes been considered and rehearsed as *inner conversations* before broaching the subject with the partner, and participants carefully gauged when and how much to say.

Protective buffering is defined by Manne et al (2007) as hiding worries and concerns from a partner and avoiding disagreement in order to reduce stress and burden. It is often viewed as an unhelpful coping strategy in couples facing cancer because it may deny each partner the opportunity of support from the other (Langer, Rudd and Syrjala, 2007; Manne et al, 2007). However,

my study's findings link more to Rolland's (2004) more nuanced position on what should or should not be shared with a partner:

> *"The healthy use of minimization or selective focus on the positive, as well as timely doses of humour, should be distinguished from pathological denial".*(Rolland, 2004, pp 233)

Rolland (1994) emphasises that in terminal illness all thoughts need not be communicated to a partner. Goldsmith and Miller (2014) also draw attention to the complexity of how couples talk about cancer. Monroe & Oliviere (2009) state that denial can exist at many levels and sometimes be helpful, sometimes not. For the participants in this study not speaking did not constitute denial. It is often not a case of *whether* a particular topic should be addressed but *how, why, when* and *in what context*. As illustrated in the study, a subject which had been taboo between a couple can become not only possible but necessary to discuss. There are multiple positions of knowing, acknowledging and giving voice to difficult issues. Participants moved between them depending on the context. Speaking out had to be balanced with keeping hope alive, even if for the short term future. Penn (2001) eloquently describes a dilemma which may face couples encountering serious illness and fits well for some of the couples in this study.

> *"I am afraid if I do not speak to you and tell you how I am, I will slowly withdraw and leave you; however, if I do speak to you, I am afraid you will slowly withdraw and leave me"* Penn (2001, pp 39)

Weingarten (2000) makes a similar point. She reminds us that until relatively recently it was considered good practice in the U.S. to conceal a terminal cancer prognosis from the individual, consequently denying the family the opportunity to grieve together. Fredman (1997), reviewing death talk in the bereavement literature, describes paradoxical messages from professionals: people *should* talk about death but *can't* because they don't know how to. Professional views of how death should be talked about may favour openness without appreciating personal and cultural contexts. While for some couples

sharing fears and mourning together may be desirable and reinforce couple narratives of closeness and transparency, some people who are dying may feel burdened by their partner's sorrow and prefer to preserve a relational narrative of their partner as being *fine*. Weingarten (2013) discusses some of the complexities of self-disclosure in couples coping with serious illness. She observes that the ill partner may already be disclosing a great deal so the partner's self-disclosure potentially promotes mutuality. Weingarten (1991) emphasised that the co-creation of meaning is more relevant in creating intimacy than sharing information in couples facing chronic illness.

This study highlights the complexity of spoken and unspoken narratives for people caring for a partner with a terminal illness. Speaking out, giving voice to fears and distress, can support couple narratives of intimacy and transparency and increase mutuality. Remaining silent can deny both partners the possibility of mutual support. The findings connect with theories such as protective buffering and help to elaborate communication theories at the end of life by examining how couples co-create meaning in their individual and couple narratives.

Narratives of loss

This study has highlighted how the process of accepting that an illness is terminal, that a partner is dying, is complex, nuanced and sometimes contradictory. A funeral can be considered while making plans for a holiday which may never happen. Plans for a medium term future alone can be considered but the moment of death cannot. The absence of the partner, the vacuum left behind, is perhaps the hardest to conceptualise or accept. For people who have lived their life as part of a couple the idea of being alone is understandably daunting, an unknown territory. Some participants had never lived alone and were uncertain how they would cope. Each of the participants were faced with constructing an altered self-narrative for the future, no longer as part of a couple.

The participants' knowledge that their partner is dying underpinned the narratives in the study. Although most identified some positive elements in the period since the terminal prognosis, all were facing a major impending loss. As Rolland (2004) observed, in terminal illness the grieving process may begin long before the actual bereavement. All the participants accepted at some level that their partner was dying but there was considerable variation in how this knowledge had been incorporated into either individual or couple narratives. The impact of loss was informed by the life-cycle stage (Rolland, 2004); losing a partner when children are still young represented a particular challenge.

This study highlighted how the anticipated death of a partner involves many layers of loss, some experienced currently, some for the future. These included the loss of the partner as they were (Weingarten 2013), the loss of the life enjoyed together, the loss of the relational narrative and the loss of the imagined future together. Incorporated within the latter may be the loss of the person with whom to reflect back on a shared past, the joint curator of memory. Most participants mourned the loss of an imagined future together and several described the loss of their previous life, although some worked to preserve this. For others, the relational narrative of their partner was sustained, despite deterioration in their physical condition. Participants worked to avoid the partner's identity and the couple narrative being subsumed by the terminal illness.

Weingarten (2013) identifies how *self-loss / other-loss* and the reciprocal connections between them may impact upon couples facing chronic or terminal illness. She defines *self-loss* as the chronic sorrow associated with the personal experience of illness and *other-loss* as the partner's loss of the ill person as they were. Partners of people who are ill also experience *self-loss* when not meeting personal or societal ideals as a caring, compassionate partner. In this study participants worked to sustain their relational narratives of their partners to counter *other-loss* and worked to sustain self-narratives as caring partners to counter *self-loss*. In terminal illness, Rolland (2004) describes possible emotional responses to anticipatory loss, including:

separation anxiety, existential aloneness, denial, sadness, disappointment, anger, resentment, guilt, exhaustion and desperation. Most of these responses were represented by some participants in the study. Estelle in particular expressed many of these powerful emotions: a reaction to her current stress and the loss of her expected future narrative of family life. Rolland reminds us that there may be fluctuation between these negative experiences and positive periods of heightened intimacy and appreciation of life together; this was seen in some of the narratives.

This study demonstrated multiple aspects of loss involved in accepting that a partner is dying. The process is complex and sometimes contradictory. Loss is many-layered: participants were losing the person with whom they had constructed self and couple narratives over many years, losing the life enjoyed together, losing their imagined future narrative and losing the person with whom to reflect back on past narratives. Participants were losing their relational identity and faced with constructing an altered self-narrative for the future, no longer as part of a couple.

The narrative typology

In this study the purpose of the typology is to highlight archetypal storylines across the narratives of people caring for a partner at the end of life. Like Frank (2010), I believe a typology can be helpful in appreciating significant features of the individual stories, and could be useful in the analysis of others in the future. I have identified three narrative types in this study: *blow-by-blow, champion* and *resilience* narratives. Hydén (1997) critiques typologies of illness narratives such as those of Frank (1995) and Robinson (1990) as being limited in their range of narrative genres. I recognise that the narrative types identified in this study do not encompass all features of the participants' narratives. They represent important aspects of how participants constructed the illness story and how identity was performed in the narratives. They are intended to complement rather than replace the analysis of narrative themes.

The typology is in no way an attempt to finalise or limit the individual stories and one narrative may contain elements of all three types.

The blow-by-blow narratives

The term *blow-by-blow* was chosen to illustrate the relentless progress of the partner's illness as described by participants. These accounts are personal and couple narratives of the illness story as constructed by the partner. They could be compared to what Gawande (2014, pp 208) describes as the *ODTAA (one damn thing after another) syndrome* when describing the progress of metastatic cancer. Some aspects of the blow-by-blow accounts resonate with Frank's (1995) description of illness narratives. They are often related as if in the present by the use of direct speech. In addition to this device bringing the story alive for the listener, it also emphasises that, for the teller, the story of the illness is current. The account is related with the teller's knowledge of the outcome and the unfolding chronological account introduces suspense into the story for the listener; details (such as symptoms) are highlighted for the significance which becomes evident as the story progresses. The level of detail in the accounts is a rhetorical device for claiming authenticity.

Wren (2012) comments that stories of important life events are refined over time and in different contexts of telling. These accounts may have been rehearsed and retold many times; they may have been edited and the significance adjusted in the light of subsequent knowledge or experience. Although related by the participant, these accounts had probably been co-constructed with the partner over time. The work of the *blow-by-blow* narratives is to find some coherence and meaning in stories of a major biographical disruption and to *bear witness.*

Frank (1995) claims that what makes for a *good story* is a story's narrative truth and the act of *witness.* He was referring to an individual's capacity to bear witness to their own illness. The *blow-by-blow* narratives are witness stories; the participants are bearing witness to their partner's terminal illness, the couple's experience of it and their personal experience. They are in turn

inviting the listener to witness their story. In so doing the narrator is, as Frank terms it, *rising to the occasion*. They are taking a moral position in telling a story which should be told. These narratives highlight the important role each participant played in their partner's illness journey and set the context for the *champion* narratives described below.

The champion narratives

The champion narratives relate how the participants became their partner's advocate and defender at a time when the partner was least able to stand up for themselves. In so doing, participants are sustaining self-narratives of strength and resilience and reinforcing their relational narratives as supportive and protective partners.

The care provider's role of advocate has been described in the care literature; (Stajduhar, and Cohen, 2009; Mcilfatrick et al, 2006). All of the participants identified instances when, in their view, their partner's needs were not being adequately met, either by the medical system or other services. Intervening on behalf of their partner appeared to bring some satisfaction to the participants, restoring a sense of agency at a time when they felt powerless against the disease and perhaps the medical system. The identity of champion was underscored by participants' narratives of justice. While some gave accounts of the injustice of their partner's illness or treatment, all indicated a desire to do what was right by their partner. Frank (1995) and Wren (2012) emphasise the importance of taking account of narrators' ethical positions. Both in their narratives and in choosing to speak out, participants are taking a moral stand. The identity of champion allowed participants to challenge privileged discourses, such as that of medicine. This has been described in illness narratives by Mishler (1984) and Frank (1995).

The resilience narratives

The participants' narratives all demonstrated resilience. All drew upon previous self-narratives of strength and resilience to navigate their current

situation. These included personal narratives of competency and overcoming past difficulties and couple narratives of closeness and strength through adversity. Participants constructed strength as being drawn from both positive and challenging past experiences. Bonanno (2004) examined resilience in those experiencing bereavement and other adverse events. He identified the characteristics of resilience as hardiness, self-promotion and positive emotion such as laughter. Hardiness is defined as being committed to finding meaning and purpose in life, a sense of agency and a belief that one can learn from both positive and negative experiences. This concurred with how participants in this study constructed their self-narratives. The description of self-promotion fits Colin's self-narrative and most participants used humour in the interviews and in accounts of interactions with their partners.

Participants in this study constructed themselves as adaptable, capable and resilient; Payne (2007) and Bonnano (2004) reported similar findings. Payne comments that while service provision for end-of-life care is often built upon a deficit model, this is not appropriate for many carers.

This study highlights the reciprocal connections between narratives of resilience and strategies which support strength and confidence. Resilience narratives enabled participants to take on challenges such as learning the technical skills of providing care and performing the identity of champion. These narratives supported survival strategies such as Estelle continuing to work while caring for her husband and children. Epiphaniou et al (2012) identify a number of strategies employed by care providers. Resilience narratives informed short-term hope by focusing on the positive rather than worrying about the future. All these strategies worked to increase participants' sense of agency and confidence, reinforcing narratives of resilience. Waddell (2015) uses the metaphor of *endoskeletal and exoskeletal* to highlight the difference between resilience, inner strength built up internally over time, and external survival strategies which can also protect and strengthen. This fits with the self-narratives of participants in this study.

Couple narratives of resilience were also highlighted by the study. Participants drew on past couple narratives of surviving and overcoming adversity together when faced with the terminal illness. Rolland (1994) proposes that resilience can help couples to overcome relationship *skews* (imbalances) when facing illness.

How does the typology identified in this study relate to Frank's (1995) typology of illness narratives?

Frank's three narrative types - the *restitution, chaos and quest* narratives - address personal experiences of illness but some aspects are pertinent to this study and my typology. The *restitution narrative* could be considered in the early stages of the partner's illness, when for some couples there was a shared belief that the illness could be *cured* by a timely intervention by the medical system. As the illness progresses despite these interventions and the hope of a cure recedes, the couple enters into the territory of the *chaos* narrative, where nothing makes sense: there is no coherent story and the future is unclear. The illness may not be embodied in the caring partner but it is impacting upon both partners. The *blow by blow* narratives work to overcome the chaos narrative by finding some order, coherence and meaning in a chaotic, out-of-control story. The *champion* and *survivor* narratives may also be understood as attempts to overcome the c*haos* narrative. They work to re-establish the agency of the narrator when events outside their control could overwhelm them or threaten their identity, thus reinforcing self-narratives of strength and resilience.

Frank describes *quest* narratives as meeting and accepting illness head on. He views *quest* narratives as the only stories where the narrator is the active voice. They are relevant to this study in that some of the participants who, having shared the illness journey, have similarly come to a degree of acceptance. Rather than battling the disease or seeking a cure, their focus is on valuing the life they have had and making the most of the time they have left with their partner. It resonates with narratives such as Valerie's which

highlight how wisdom and understanding can be gained through surviving adversity.

Summary of the typology

The typology identifies significant features from the narratives which I have linked to the relevant literature and to Frank's typology. The narrative types identified do not represent the full range of issues raised in the narratives and are intended to complement rather than replace the analysis of narrative themes. The *blow-by-blow* accounts examine how participants construct the illness story and their place within it, while *champion* and *survivor* narratives foreground privileged, positive identities constructed to negotiate the experience of caring for a dying partner. Other important elements, such as narratives of loss and other aspects of the couple relationships, are explored in the analysis of narrative themes.

In focusing on the narratives of people caring for a dying partner, this typology represents a departure from existing typologies which have focused primarily on personal illness narratives. In identifying narrative types specific to this group, this approach offers a contribution to the literature on partners of people with a terminal illness. Although not intended to encompass all aspects of the participants' narratives, the typology proposes archetypal narratives which could be adopted in future studies.

Strengths and limitations of the study

In this section I will reflect on what claims can be made for this study, critique the chosen methodology, address the challenges and limitations and consider whether the study has addressed the research question.

What can this study claim?

This study provides a detailed view of the experiences, relationships and identities of people caring for a partner with terminal cancer. The study highlights how personal, relational and couple narratives were sustained and reconstructed by participants to give meaning and coherence to their lives as they care for their partner. The strength of this study is based upon the quality of the data and the analysis. The analysis of narrative themes illustrates how a range of participants' experiences and relationships are constructed through narrative. The typology, as discussed above, offers a template of archetypal narratives specific to people caring for a partner at the end of life. This offers an original contribution to the literature on people caring for a partner at the end of life.

Critique of the methodology used

The methodology chosen for this study is dialogical narrative analysis informed by the work of Riessman (2008) and Frank (2010). The methodology each had applied to personal illness narratives was adapted to focus on the personal and couple narratives of people caring for a partner at the end of life. I believe this was a good choice for this study. It allowed for the detailed exploration of how caring and couple relationships were constructed in the context of end-of-life care. It illustrated how identities were performed and past narratives drawn upon. It was effective in highlighting the complexities of spoken and unspoken narratives and acceptance of loss. The typology identified archetypal narratives specific to this group. Hydén (1997) has critiqued typologies such as those described by Robinson (1990) and Frank (1995) as being limited in their range of genres. The same point could be made about my typology: it does not represent all aspects of participants' narratives. The analysis of narrative themes is more comprehensive.

Gunaratnam and Oliviere (2009) have critiqued the role of narrative in palliative care, taking account of issues such as *creditworthiness* and practical application, and conclude that there is a need for critical examination of narrative work. The issue of *creditworthiness* is also raised by Riessman

(2008) and Andrews et al (2008). Riessman maintains there are no abstract criteria for validation to fit all projects. I tried to represent participants' narratives accurately but recognise this work is my interpretation. Paley (2009) highlights the confusions and assumptions sometimes found in narrative and warns against attempts to omit inconvenient facts in trying to achieve consistency.

Frank (2009) also warns of the dangers of narrative including: imposing form on stories, the possibility of coercion, moral insularity and *genre* problems. He highlights the dangers inherent in *heroic* stories. I have been aware of these dangers as I have conducted this research. I was conscious that in interpreting narratives I could be making assumptions. I was aware that in creating a typology there was a danger of fitting a narrative into an existing frame or genre: as Frank (2010) terms it, *finalising it.* I believe that the sustained focus on individual narratives before looking across them was helpful in this, as was sharing data and analysis in supervision and data analysis sessions.

Challenges and limitations of the study

The first challenge in undertaking this research was to negotiate the complexity of NHS, university and hospice ethical approval systems. In a study in such a sensitive area, I recognise the need for processes to ensure any risk to participants is minimised. Addington-Hall (2002) discusses the ethical issues for research in palliative care. The second challenge was in recruitment. I was recruiting participants, from several hospices, over 15 months but did not recruit the number originally intended. Extending the inclusion criteria to other diagnostic categories did not yield further referrals. It is possible that extending the criteria to include participants whose partners were not in the *late-stage* of cancer (defined in this study as the last 6 months of life) could have resulted in more referrals but it would have changed the focus of the study. Participants would have been less likely to be providing care and may not yet have been reflecting on some of the issues focused on in this study. In retrospect, I do not consider the reduced number of

participants to be a disadvantage as it allowed for closer attention to each narrative. There is no consensus on sample size for a study such as this (Baker & Edwards, 2012) and many narrative studies are based upon single case examples (Riessman, 2008). At the same time, the study was limited by the relative lack of diversity and the fact that all of the participants portrayed strong, overall positive, couple relationships.

At the beginning of this study I gave considerable thought as to whether to interview the ill partner in addition to the caring partner (this issue is discussed in the methodology chapter). Over the course of the study I have continued to review this decision. I recognise that in interviewing both partners I would have gathered a more comprehensive view of couple and relational narratives. At the same time, some of the ill partners in this study were close to death and it would have been hard for me to ethically justify interviewing them about their couple relationship. There have been few narrative studies interviewing both partners in the context of illness, Skerrett (2003), Little et al (1999, 2000) and, in palliative care, Murray (2003). In a future study, partners could be included in a study similar to mine but perhaps with an altered timeframe; the methodology could be adapted to allow for this.

Only half the participants completed a journal and I have considered whether it was justified to use this form of data gathering. I had concerns that journal-keeping could be burdensome to people caring for a partner at the end of life and did not put any pressure on participants to write one. Although only three journals were completed, they did provide an additional perspective on the individual narratives in showing how the participants constructed their written selves and highlighted aspects of their day-by-day life. One of the journals represented self-narratives not apparent in the interview. For these reasons, plus the fact that two of the participants found writing therapeutic, I consider that the journals were worthwhile. Stone, Shiffman, Schwartz, Broderick and Hufford (2002) found journal compliance was much higher in participants using an electronic rather than a paper journal to record pain. The one participant in this study to use email was certainly prolific but the method would not suit all.

A possible disadvantage of using two methods of data analysis was the danger of repetition but, in practice, the analysis of narrative themes and typology complemented rather than duplicated each other.

Was the research question addressed?

The chosen methodology proved effective in addressing my research question. The study produced a detailed picture of the experiences, identities and couple relationships of people caring for a partner with terminal cancer at a particular time in a particular context. It illustrated how participants utilised individual and couple narratives to construct their experience.

Quality

In assessing this thesis for quality as a qualitative study I have primarily drawn upon the guidelines identified by Elliott et al (1999) and Potter and Hepburn (2005). I have linked this study to the relevant literature, my research question was clear and I believe my methodology (dialogical narrative analysis as described by Riessman (2008) and Frank (2010)) was appropriate for addressing them. I gave careful consideration to the ethical issues of research in this sensitive area and obtained appropriate informed consent. I have been specific in detailing the methods employed and tentative in drawing implications or making generalisations from the data.

I specified my theoretical, professional and personal positions regarding the research and, over the course of the study, have continued to examine how my assumptions and personal experiences could be colouring the way the interviews were conducted and the data interpreted. As suggested by Potter and Hepburn (2005), I have been specific about how the interviews were set up and have considered how this may have impacted on the content and process of the interviews. In accord with Riessman (2008), Frank (2010) and Potter and Hepburn (2005), I have recognised the interactional nature of the

interviews and consider the data as co-constructed between each interviewee and me. I have thus included my contributions in the transcriptions and analyses.

As recommended by Elliott et al (1999), I have *situated my sample* by giving descriptions of my participants and their life circumstances as relevant to the study. Throughout the study, I have given specific examples of data to illustrate analytical procedures and have related my findings to particular examples in the data, both in the individual and cross-case analyses. The authors cite the importance of *credibility checks*: I have made use of every opportunity to share my data with colleagues and to open up my analysis to scrutiny. The feedback from my supervisors and peer group has been invaluable in developing my thinking and helping me to recognise potential blind spots. The final issue raised by Elliott et al is concerned with how the study resonates with readers. The feedback received so far suggests that readers find the study both interesting and moving. The nature of the topic, the focus on individual stories and the inclusion of data all contributed to this.

Revisiting self-reflexivity

Relational reflexivity

In conducting the interviews, I adopted the stance recommended by Frank (2010) of *standing beside* participants, trying to appreciate their perspective and elicit their stories. At the same time I recognised my part in co-constructing the narratives. I tried to make the interviews an overall positive experience. When transcribing, it became clear that in some instances I had taken an active role in supporting the performance of a particular identity, for example Deidre's *champion* or Valerie's *adaptable survivor.* This was my way of providing encouragement to participants at a difficult time. There is a possibility that this acted to silence other less privileged voices.

My relationship with each participant remained that of a researcher / interviewee. This was facilitated by the set-up of the interview, my interviewing style and the context, in the participant's home. I had a good rapport with all the participants but was aware that my relationship with each was different. This was partly determined by the commonalities and differences between us (Burck 2005). The women in the study showed more curiosity about my life than the men and made connection through similarities between us, whether as mothers, carers, fellow professionals or through a shared sense of humour. This connection probably enabled them to speak more freely with me. The first interview was influenced by the fact that the participant, Anna, was a fellow mental health professional. Anna positioned herself as a colleague from the outset, expressing interest in the research and several times adopting a reflective *meta-position*. This interview felt closer to a therapy session at times because of the emotional content and I felt a pull towards positioning as a therapist but I maintained the position of a researcher.

I was aware of feeling gratitude towards the interviewees, possibly related to the difficulties of recruitment, discussed by Liamputtong Rice and Ezzy (1999). This could have affected the research relationship and my analysis. I believe that although I expressed my gratitude profusely it did not otherwise impact upon the research relationship or outcome of the interviews. I also felt protective of participants. This was illustrated when presenting data at a data analysis session. I had privileged one participant's narrative of bravery and honesty at the expense of some of the more vulnerable aspects of her story. This was highlighted in discussion and I was able to take a more nuanced position. These issues underline the importance of supervision and feedback to sustain self-reflexivity.

Relationship to narratives

When conducting the analysis my initial tendency was to stay close to the participant's voice. At the time I viewed it as doing justice to the narratives. As I worked further on the analysis, however, I recognised that this limited my scope. Feedback from supervisors and peer group was very helpful in this

regard as were the strategies suggested by Frank (2010): writing letters to the participant and the narrative and writing a narrative from the perspective of another character. One example of this was in the narrative I wrote from the perspective of Deidre's daughter (Appendix XV). Deidre had represented her children's behaviour as unsupportive and incomprehensible. Writing from her daughter's perspective helped me to explore possible alternative meanings in Deidre's family narrative. These included differences in cultural expectations of familial support between generations and the daughter's uncertainty as to what her mother wanted from her, given the mixed messages she had received.

Managing the tension of my relationship to the data was an essential part of the research process: close enough to appreciate the subtleties of the participant's perspective and distant enough to analyse it critically to allow further meanings to emerge. The process of conducting the cross-narrative analysis enabled me to adopt another position with the data which then allowed me to revisit the individual narratives from a fresh perspective.

In the analysis and writing-up of the thesis, I have also become aware of my desire to *tell a good story*. This was at least partly informed by my wish to *do justice* to the participants' accounts. I wanted my account to engage the reader as the participants' narratives had engaged me.

Avoiding therapeutic interpretations and therapist as researcher

A further challenge for me in data analysis was to avoid the trap of interpretation as a therapist rather than as a researcher. For example, I would make suppositions based upon a participant's early experiences rather than focusing on the narrative. Nevertheless, I believe my background as a therapist was a considerable advantage in conducting the interviews, in terms of following feedback and exploring meaning. In the analysis it was helpful in terms of self-reflexivity and consideration of multiple positions. Burck (2005) and Wren (2012) identify the qualities which clinicians can bring to research.

The emotional impact of the data

The emotional intensity of the interviews and data influenced my choice of language in the process of analysis, such as choosing the heading, *Looking into the abyss* before re-naming this section as *Narratives of loss.* Supervisory feedback helped to ensure the concepts identified were congruent with my chosen methodology. My initial tendency to focus on description rather than critical analysis may also have been due to the emotional impact of the narratives. This was addressed by supervisory feedback and by constant referral to a list of questions to interrogate narratives, based on the work of Riessman (2008) and Frank (2010)

My position on spoken and unspoken narratives

What can and cannot be talked about between couples was a key issue in this study. In conducting the research I have also re-examined my own position regarding speaking out and sharing distress as opposed to protecting partners or family members by remaining silent. Fredman (1997) has considered this issue in detail, noting the importance of acknowledging both clinicians' and families' beliefs. Over the course of this thesis I have gradually appreciated the complexity of my own beliefs regarding speaking on sensitive issues. I realise it is possible to simultaneously hold multiple positions on sharing distress, based upon previous narratives, and these may at times appear to be contradictory. In my own case I share my medical family of origin beliefs concerning transparency regarding prognosis and the practicalities of death. At the same time I have come to a more nuanced position, taking more account of relationships, timing, context and cultural considerations. I also believe that *protecting* an ill person from one's own or another's distress may sometimes be the *right* thing to do; when someone is dying, they may not wish to or be able to deal with someone else's distress. In the study several participants made strong statements about their belief in transparency and still protected their partner from their sadness. I came to realise the importance of owning my own *multiple positions* to challenge any assumptions about what participants should or should not be revealing to their partner.

Impact of the order in which interviews were conducted

The interviews and analysis were conducted in the order in which I received the referrals. Although I endeavoured to approach each interview with an open mind, inevitably my stance and questions within each interview were influenced by my assumptions based upon personal and professional experience and my reading of the literature. Similarly, the way I conducted each interview was influenced to some degree by the previous interviews. This process may have been heightened by the extended time between interviews allowing me to focus on data analysis before the next interviews. Issues which were prominent in early interviews may have primed me to picking up on similar issues in subsequent interviews. For example, the first interviewee gave a vivid description of her response to an unhelpful GP receptionist and similar issues were noted in several later interviews, eventually supporting the identification of the "champion" narrative type. Another example is that in earlier interviews I became aware of how participants worked to sustain valued aspects of the couple relationship and life together, this awareness prompted me to *tune in* to similar narrative threads in subsequent interviews. Frank (2010) warns of the danger of narratives reinforcing each other in an iterative fashion and emphasises the importance of being open and valuing each story on its own terms rather than fitting them into an existing framework. At the same time, sensitivity to some of the more subtle elements in a participant's story can be enhanced by previous narratives and add to richness of the overall narrative.

Example of an ethical dilemma in the study

Dickson-Swift et al (2007), highlighting some of the sensitive issues which can arise in a qualitative interview, observed that a research interview may provide the space for participants to disclose information not previously shared with anyone. This may be due to the rapport created, the lack of other people in whom to confide or even the fact that the participant will not see the researcher again.

In this study Brian, the 63 year old man who had been married for 40 years, told me at the end of the interview that, when his wife died, he*, "had thought about going with her."* Brian had not discussed these thoughts with anyone else. He did not present as depressed and was not describing intention; I understood it as an expression of how difficult it was to contemplate life without his wife, Beth. I discussed the issue with my research supervisor and twice more with Brian in follow-up phone calls. The dilemma for me as a researcher was to balance the ethical requirement to ensure Brian's welfare and the obligation to respect his confidentiality.

I asked Brian if he would agree to me contacting the hospice services on his behalf (he was attending a carers' group) but he declined. He assured me that he would not *"do anything stupid"* because of his family. I again strongly encouraged him to discuss his thoughts with the hospice team. In this instance, taking account of risk, autonomy and confidentiality, I believed the ethical choice was to respect Brian's choice.

What surprised me about the study

I was surprised both by the difficulty in recruitment and the enthusiasm of the people who did agree to take part. All were keen to tell their story and for their voice to be heard. I was surprised at how positively participants constructed both their experiences and their relationships. This could be attributed to the likelihood that people in positive partnerships who were coping well with caring for their partner could be more inclined to participate. It could also be that at the end of couple life together people may prefer to reflect on and represent more positive aspects of their relationships.

This study has reminded me of the potential strength and endurance of the couple bond and the ethical positioning of people caring for a dying partner. I have great respect for all the participants in this study. I have learnt that dialogical narrative analysis can be a valuable tool in exploration of meaning in narratives such as these.

The clinical implications of the study

Although the findings of this study are specific to a particular group of participants at a particular time, some aspects highlighted by the study could be of particular relevance to couples facing a terminal illness and clinicians addressing relationship issues with them.

In the face of loss it was important to participants to preserve previous couple narratives, valuing and revaluing the positive aspects of couple life such as intimacy and mutuality despite the limitations imposed by the illness. Participants' construction of themselves as joint partners in facing the terminal illness reinforced positive self and couple narratives. A clinician working with couples at the end of life could use awareness of these ideas to underline and reinforce positive elements of the couple relationship and perhaps explicitly explore how valued aspects could be sustained at a practical level. In addition clinicians can provide a safe context for the consideration of more challenging facets of the couple relationship.

The life-cycle stage of couples in the study was critical in how the prognosis was received and clinicians may find it useful to consider the implications of this with couples, keeping in mind how constructions of illness and the couple relationship may change over time and the progression of the disease. The study highlighted the complexity of the anticipated loss, including loss of the partner, loss of relational identity and loss of the imagined future. Systemic therapists are well placed to explore these issues in depth with both couples and individuals.

The study underlined the complexity of spoken / unspoken narratives between couples at this time and suggests there is no *right* way for couples to discuss end-of-life issues. Timing is critical: couples may fluctuate and may not be ready to discuss issues at the same time as each other. This finding is congruent with the positions of Altschuler (2015), Rolland (1994) and

Fredman (1997). Similarly, acceptance that a partner is dying can be a complex, nuanced process and hold contradictions within it. The study underlines the importance of sustaining short term hope at these times. Recognition of the complexity and potential dissonance of these important issues for couples could enhance clinicians' understanding and inform more sensitive and effective interventions. It may be important for clinicians to consider offering individual sessions in addition to couple sessions to explore issues of particular sensitivity. Couples may not be ready to explore issues of loss at the same time and the fear of upsetting the partner could preclude discussion of issues important to the individual.

The typology identified in the study could provide a useful template for clinicians when considering how experiences and relationships are constructed by partners of people who are terminally ill. The *blow-by-blow* accounts emphasise the accumulative impact of the illness trajectory on individual and couple narratives. The study has indicated the importance of these accounts for the ordering and making sense of a traumatic period in couples' lives and the importance to participants of being heard. A professional listening carefully to and appreciating these narratives could be both illuminating and therapeutic. The *champion* and *resilience* narratives show how the performance of identity can reciprocally construct and reinforce self and relational narratives of strength to better manage this period. Participants drew upon previous narratives to assist this construction. I suggest that therapeutic intervention, for example narrative therapy (White and Epston,1990) could also support this process. Further detailed examination of the positive personal stories and aspects of the couple relationship could enhance and underline narratives of strength, sustain a sense of agency and perhaps enable multiple positions to be explored.

Much of the literature on the couple relationship at the end of life has been based on clinical populations and there may be an assumption that therapeutic intervention is desirable for people experiencing the loss of a partner. Bonanno (2004) challenges this view, stating that resilience is more common than previously believed and that *grief work* is only necessary for a

small subset of those faced with loss and can even be unhelpful. He emphasises that there can be multiple reactions to loss.

None of the couples in this study were receiving couple therapy, although one couple had seen a counsellor on one occasion. The study suggests that, although losing a partner may be the most traumatic event in most people's lives, people do not necessarily need therapy to address it. At the same time, I accept that there may be many instances when a timely intervention by an experienced therapist could be invaluable to an individual or couple. Acworth and Bruggen (1985), Rolland (1994), Kissane and Bloch (2002), Weingarten (2013) and Altschuler (2015) provide multiple examples of when and how systemic interventions can be helpful for couples facing terminal illness. Participants in the study who had attended hospice support groups for care providers had found them helpful (Harding et al 2004). For one couple who had attended hospice groups, this had facilitated communication between them.

For the participants in this study, reviewing their lives together ensured past narratives are reworked and preserved for the present and the future without the partner. These narratives could be a valuable resource for participants in the bereavement process and beyond. Although most participants had embarked on this process spontaneously it could be facilitated and enhanced by clinical intervention. Butler (1963, 2002) describes life review as having potential therapeutic benefits. Some studies, based upon the work of Butler, have evaluated life review as an intervention with older adults. Bohlmeijer et al (2003) and Peck (2001) note the benefits of life review for individuals at the end of life in terms of subjective wellbeing. Chochinov et al (2011) found d*ignity therapy*, an intervention which gives people nearing death the opportunity to speak about the things which matter most to them, was helpful for both the individual and their family. There are fewer studies focusing on couple life review. Caldwell (2005) describes narrative interventions which facilitate life review of older adults and their caregivers and Retzenbrink (2009) highlights the importance of *witnessing* the stories of people whose

partners are dying. This study supports the potential of narrative interventions for couples at the end of life.

A research study is not intended as an intervention but it was apparent that the narrative interviews had a positive impact on the participants in prompting reflection on identity and relationships and allowing less privileged narratives space. It appeared that the act of listening to and witnessing of the experiences and meaning-making for participants was as important as more targeted interventive questions. At the same time, some of the questions utilised in the research, for example those questions which invited reflection on changes to personal and relational identity, could be used in a clinical context. This suggests that similar conversations with a clinician or other could be beneficial for people caring for a terminally ill partner. Several of the participants described participation in the study as *cathartic*. This was also found by Watts (2008) and Dickson-Swift et al (2007). The potential of journals as a therapeutic tool was suggested; Valimaki et al (2007) identified positive effects of diary keeping. As Penn (2001) observed, writing can bring feelings into consciousness and language, allowing us to rehearse what has never been spoken and allowing the expression of alternative voices.

In summary, the most important clinical implications of this study are as follows. The study underlines the value of a systemic perspective when working with couples facing a terminal illness. The complex interplay between personal and relational identities highlighted in the study could be addressed by systemic clinicians. I have demonstrated how couple relationships and the social context mediate meaning and experience for the caring partner. Relationships and the terminal illness are shown to reciprocally impact upon each other. This focus on the relational may be of particular value to those working with individuals and families in a hospice setting where interventions have historically been aimed at the patient and the carer but, as Forbat (2009) has observed, not always at the care relationship.

For therapists working with couples at the end of life the study offers further insights. Using a narrative framework I show how people caring for a

terminally ill partner construct their identities, experiences and relationships. I show how the terminal illness is contextualised within overall personal and couple narratives. The study highlights issues which could be fruitfully explored with couples experiencing relationship difficulties at the end of life. These include the complexities of spoken and unspoken narratives and how these are determined. A clinical setting can provide a safe space for the gentle exploration of what can be spoken, when and how. The implications of both speaking out and remaining silent can be addressed. The multiple layers and subtleties of loss described in the study could be helpful to clinicians working with both couples and individuals. The importance of sustaining previous couple narratives was a significant finding in the study and an issue which could be usefully explored and enhanced in a clinical setting. The interviews underlined the importance for people caring for a partner to bear witness to their experience and to be heard and witnessed themselves.

Suggestions for further studies

This study raised some important issues regarding how caring partners construct their experiences, identity and relationships. At a time when an increasing number of people are caring for a terminally ill partner, there is a good case for further research. A larger study using similar narrative methodology could be a useful addition to the literature. This could allow for more diversity in terms of ethnicity and types of couple relationships and could further extend our understanding of the experiences, identities and service needs of caring partners. Bingley et al (2008) note the importance of attending closely to both patients' and carers' narratives to improve our understanding of individual needs and in the development of policy and practices effective in supporting people at the end of life. The typology identified could be a useful tool in future studies in providing a template for considering the narratives of partners of people with a terminal illness. A larger study could further explore the typology's relevance to people caring for a partner at the end of life or suggest alternative narrative types.

There may also be scope for learning more about the couple relationships of terminally ill patients and their partners in future studies using similar methodology but involving both partners. The ethical and practical issues would need to be carefully considered and the timeframe adjusted accordingly. A study involving both partners interviewed both separately and together could provide additional perspectives on how spoken and unspoken narratives are constructed and utilised by couples facing terminal illness. The co-construction of couple narratives of resilience and *blow-by-blow* accounts could be elaborated by a study involving both partners. Although conclusions cannot be drawn from such a small sample, I would agree with Valimaki et al (2007) that journals have potential as a research tool and as a therapeutic option for those caring for a partner at the end of life.

Conclusion

This study focuses on the identity, experiences and relationships of people caring for their partner at the end of life and examines how their experience was constructed through narratives. The most significant findings are as follows.

Participants constructed individual and couple narratives to find meaning and coherence at a time of extreme biographical disruption, the anticipated loss of their partner. The impact of the loss was informed by the couple's age and point in the life-cycle. Past narratives of loss were also important in how the impending loss of a partner was received. *Loss* encompassed loss of the partner, loss of the imagined future and loss of the relational self. The study demonstrates how participants sustained personal, relational and couple narratives in the face of a terminal illness. Participants worked to ensure the couple narrative was not taken over by the illness.

The study highlights the complexity of spoken and unspoken narratives for couples at the end of life. Participants held multiple positions regarding what could be shared with a partner. This could change over time and altered circumstances, such as a deterioration in the partner's condition. Several participants simultaneously valued the openness between themselves and their partner *(preserving the couple narrative of closeness)* and yet shielded their partner from knowledge of their distress *(sustaining the partner's relational narrative of them as strong and resilient).* These findings indicate the issue is more nuanced than sometimes represented in the literature on protective buffering.

This study invited people to review their individual and couple narratives in the context of the terminal illness. Some participants had already begun this process, contextualising the illness and anticipated loss within the overall life story. Several participants constructed the time since the terminal prognosis as being a particularly positive period in the couple's life. The knowledge that time was limited added intensity; hope was kept alive if only for the short term. Everyday activities together took on new significance, memories were created to be treasured in the future. These *small stories* reminded participants who they were and what the couple have been to each other; they were also a reminder of what will be lost. Most participants constructed couple narratives of enduring love. It is possible that people with more conflictual couple relationships would be less likely to volunteer for a study such as this. The study highlighted that the process of accepting that a partner is dying can be complex, nuanced and sometimes contradictory.

Two complementary forms of narrative analysis were employed: a typology and an analysis of narrative themes. The typology identified in this study makes a novel contribution to the literature on partners of people with a terminal illness. The *blow-by-blow* accounts bring to life how the progression of the partner's illness and treatment is constructed by the participants. They illustrate how the participant's role and the couple relationship is constructed in relation to the illness. The *champion* and *resilience* narratives demonstrate identities performed by participants to manage this difficult period; they show

how participants *rose to the occasion,* adopting ethical positions to do what was believed was right for their partner. The typology illustrates how personal and relational narratives can be drawn upon in the performances of identity and behaviour which can then reciprocally reinforce positive self-narratives of strength and resilience. Although not encompassing all aspects of the participants' narratives, the typology proposes archetypal narratives which could be adopted in future studies.

The analysis of narrative themes allowed for focus on a broader range of issues including loss, spoken / unspoken narratives and how culture, gender and previous narratives informed the construction of experience and relationships for participants. These two forms of cross-narrative analysis are complementary.

In this study I have adapted dialogical narrative analysis to examine how people caring for a partner at the end of life construct their experience through individual and couple narratives. I have highlighted how personal and couple narratives are sustained in the face of terminal illness and the complexities of the acceptance of loss and what can be discussed between couples. A typology based upon the narratives has been identified. This study makes a contribution to an important but less researched area of the literature.

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Appendices

Contents

Appendix I
Flyer for potential participants

Research contact
Louise Anthias
Tel 07540 839885
Email: louise.anthias@gmail.com

Experiences of Caring for a Partner with Cancer at Home

Flyer for Potential Participants

Are you caring for a partner with cancer at home?
I am a researcher hoping to interview people in your situation to talk about how your experience has affected your life and your relationships. If you are interested in taking part or knowing more about the study, please let your CNS know and they will provide further information about the research. Following this, if you are happy to consider participating and give permission for your contact details to be forwarded to me, I will contact you by phone to discuss it further.

Thank you for your interest in my study!

Louise Anthias
Doctoral student at the Tavistock Centre

Version 2 23/1/12

Appendix II

Information for Participants

The Tavistock and Portman NHS
NHS Foundation Trust

Directorate of Education and Training
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Tel: +44 (0)20 7435 7111
Fax: +44 (0)20 7447 3837
Web: www.tavistockandportman.nhs.uk

Research contact:
Louise Anthias
Tel 07540 839885
Email: louise.anthias@gmail.com

Experiences of Caring for a Partner with Late Stage Cancer at Home

Thank you for your interest in this research. The purpose of the study is to find out more about the lives and experiences of people, such as you, who are caring for a partner with cancer at home.

Who is conducting this research?
My name is Louise Anthias and I am a Family Therapist currently on a Professional Doctorate programme at the Tavistock Centre in London. I have both a professional and personal interest in this subject, having worked as a therapist with couples where one partner was seriously ill and also having personal experience as a carer in the final stages of cancer, although as a sibling rather than a partner.

Do I have to take part?
No. It is your choice whether or not to take part in the study and your decision will have no effect on any services you and your partner are receiving. The Clinical Nurse Specialist will give you this information sheet. If, having read it, you would like to consider taking part, she will also ask for permission to pass your contact details to me. If you agree, I will contact you by phone, answer any queries you may have about the study and, if you wish to participate, arrange a convenient time to meet with you.

What does the research involve?
The research study is in two parts. The first part is an interview with you lasting about 90 minutes. Interviews can be conducted in your home or elsewhere but it is important that it is somewhere you feel comfortable and can speak freely. When we meet, I will first ask you if you have any questions regarding the research and ask you to sign a consent form agreeing to take part in the study and confirming that your partner is aware of the study and has no objections to your participation. I will not be interviewing your partner.

During the interview I will be asking you to talk about your life as a caregiver and how you think your experiences have affected you as a person and your relationships with your partner and family. I will record the interview on an audio recorder.

For the second part of the study I will ask you to keep a journal over the following three weeks, this may be done as an email, word document or handwritten in a notebook I will provide. I would like you to record your thoughts and reflections on your current life; ideally I would like you to write something every day, however brief. I will collect the journal from you at the end of the three weeks and talk to you about how it felt to complete the journal and participate in the study. In the case of an email journal this conversation may be by phone.

Confidentiality
I appreciate that you will be talking to me about some sensitive and private matters and will do my utmost to ensure your confidentiality. The names and personal details will be changed when the audiotapes are transcribed. The recording and transcript of the interview and the journal will be kept securely while the data is being analysed. When the study is over the tapes and transcript will be destroyed and the journal returned to you. The analysis of the data will be written up in my thesis which will be held in the library at the Tavistock Centre. If I wished to publish any material relating to you I would consult you first. I would be happy to share the findings of my study with you. Confidentiality will only be breached in the event of a participant disclosing a criminal act or intention to commit a criminal act or if I were concerned about the safety of you or your partner.

Who will be told that I am taking part in the study?
I will inform the member of the hospice team who suggested your name whether or not you decide to take part. I would not usually inform your G.P. unless I had concerns regarding you or your partner's health or safety.

What if there is something I don't want to discuss or if I change my mind about participating in the study?
I appreciate that we may be talking about difficult issues and if there are things you would rather not discuss, that is your choice. You are under no obligation whatsoever to participate in the study and if you decide at any time, for any reason that you would rather not continue, it is fine and will have no effect on any services you and your partner may be receiving.

What will be the effect of the study on me?
While it is impossible to predict the effect of participating in a research study on an individual, most people find it a positive rather than negative experience, both because it can be a relief to talk about what this period in your life has been like for you and because it can be good to know that your experiences might help others in the same situation in the future. At the same time, we will be talking about sensitive issues and, if you were to find yourself feeling upset; this would be completely understandable. If, following your

participation, you should find you do need support I would try to help you to access this through local services.

Who do I contact for further information?
Please contact me by phone or email if you have any further questions or concerns about the study.

Louise Anthias
Telephone: 07540 839885 Email: louise.anthias@gmail.com

If you wish to raise a concern or complain about the study to someone other than the researcher, please contact:

Dr Reenee Singh,
The Tavistock Centre,
120, Belsize Lane,
London NW3 5BA
Telephone: 020 7435 7111 Email: rsingh@tavi-port.nhs.uk

Thank you for taking the time to read this and for considering taking part in the study.

Version 3, 17/4/12 ***REC reference: 12/LO/0448***

Appendix III

Consent Form for Participants

The Tavistock and Portman NHS
NHS Foundation Trust

Research contact
Louise Anthias
Tel 07540 839885
Email: louise.anthias@gmail.com

Directorate of Education and Training
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Experiences of Caring for a Partner with Late Stage Cancer at Home

I have read the information sheet (version 3, date 17/04/12) for the above study and have had the opportunity to consider participation, ask questions about the study and have them answered satisfactorily.

- I understand that I may withdraw from the study at any time without it affecting any services my partner or I are receiving.
- I have discussed the project with by partner and he/she has no objection to my participation.
- I am aware of the limits of confidentiality in the study.
- I understand that the interview will be audio recorded and the recording and transcript will be kept securely and destroyed at the end of the study.
- I agree to try to keep a journal for 3 weeks after the interview but understand that I am under no obligation to do so. I understand I will meet with the researcher again at the end of this time to hand it in and discuss the experience. If I decide to send the journal as an email this discussion may be by telephone.
- I understand the journal will be kept securely and returned to me at the end of the study or email journals deleted.
- I have been informed that my personal details will be changed to protect my confidentiality in this study.
- I am aware that hospice staff will be informed of my participation.
- I agree to participation in this study.

Participant:……
Date:……...

Researcher:……...
Date:……...

Version 3: 17/04/12 *REC reference: 12/LO/0448*

Appendix IV

The Interview Guide

I propose to conduct a systemic interview in which I will elicit the participant's story of their life as carer and a partner. The following questions and prompts are examples of areas I may cover in order to address my research questions. I will not be going through the questions in a sequential way but will be following the participant's feedback and conducting the conversation accordingly. I will be responding to a participant's apparent willingness to discuss particular issues and their level of distress. I am aware of the sensitivity of the subject and will try to ensure that the interview is not an overall negative experience for the participant. I have included some questions which invite positive reflections.

Can you tell me how you first came to be caring for (partner)?
Possible prompts:

Could you describe the events that led up to this
What was going on in your life before this happened?
Would you use the term 'carer' to describe yourself?
Was it your choice to become a carer?
Would you say it was expected of you?
How has your family managed illness in the past?
Is it usual to help each other out in difficult times?
How was this negotiated?
How long has …. needed your help?

How has your life changed since you became a carer?
Possible prompts:

How well is your partner at the moment?
How much help do they need from you now?
What was your life like before and what is it like now?
What have been the losses?
What have been the positive aspects, if any?
What do you find most difficult?
Do you have any time for yourself?

In what ways do you think you have changed as a person since you became a carer?
Possible prompts:

How would you have described yourself as a person then?
How would you describe yourself now?

Do you think gender makes a difference when caring for a partner? How would you describe the difference?

Some people would say you are doing one of the hardest jobs anyone can do. How do you think you are doing with it?
Possible prompts:

How you think others (partner, family, friends, medical team) would
. say you are doing?
In which ways, if any, has it impacted on your own health?
Have spiritual beliefs been important to you at this time?

What support do you have from professionals and from family and friends?
Possible prompts:

How much contact do you have with family and friends now?
Has this changed over time?
Has your relationship with your parents / children changed since you became a carer?
In what ways do you feel supported in you role as a carer?
What further support would be helpful to you at this time?
Who, if anyone, do you talk to about your concerns?

Has your relationship with (partner) changed since you began to look after her/him?
Possible prompts:

How would you have previously described yourselves as a couple?
How has your relationship changed since then?
What have been the losses and gains?
How do you talk to each other about what is going on?
How do you get a sense of what it is OK to talk about and when?
In what way do you show your sadness or hopes and fears for the future?
Have you been able to talk about dying / the funeral?
What was it like to have that conversation?
What are the most important dilemmas you and your partner are facing at the moment?

Are you able to think about or plan for the future at the moment?
Possible prompts:

Would you say your experience has changed your priorities in life?
Have you have changed as a person as a result of your experience?
Do you have any particular advice for someone embarking on the same journey?

Is there anything else you think I should know in order to understand your experience better?
How has it been talking about these matters with me today?

Appendix V

Information for Referrers

The Tavistock and Portman NHS
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Research contact
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The Last Journey Together:

Experiences of caring for a partner with late stage cancer at home

In this study I hope to recruit approximately twelve participants who are currently caring for a partner with late stage breast or prostate cancer at home. The purpose of the study is to address the following questions:

- How do people experience caring for a partner with late stage cancer at home?
- How does the experience affect the carer's sense of self?
- What is the impact of the experience on the couple relationship?

Inclusion Criteria

- I have specified breast and prostate cancer because of their prevalence in the community and because I hope to include both men and women in the study, I would certainly be willing to include other diagnoses if it proves difficult to recruit sufficient numbers.
- By 'late stage cancer' I envisage that the partner with cancer would be in receipt of palliative care and not be expected to survive beyond six months. The caring partner would living with them and be the main carer.
- By 'partner' I include all couples who have been in a long term committed relationship prior to the onset of illness, including unmarried and same-sex partnerships.
- I would not want to exclude participants who do not speak English as a first language, although this could be contingent on finding an appropriate interpreter.

Exclusion Criteria

- Anyone who does not wish to participate in the study.
- Anyone for whom participation could be potentially burdensome, for example someone with moderate to severe depression.

What the research involves
The research involves a semi-structured interview lasting between one and a half and two hours. The interview will be recorded. Following this I will ask participants to keep a journal of their experiences and reflections over a three week period. Finally I will meet again with the participant to collect the journal and conduct a short 'debriefing' interview with them.

Recruitment

- When the referrer identifies someone who may be appropriate for the study, I would like them to give brief details to the potential participant (see flyer) and, if they are interested, issue them with a participant information sheet and consent form. If the partner is happy to consider taking part in the study, they should give permission for contact details to be forwarded to me, together with a time convenient to be contacted. Please use my phone number / email above.
- I will contact potential participants by phone, giving further details of what the project involves and ensuring their partner is agreeable to their participation. If the participant is willing to proceed, I will arrange a time to interview them, probably in their home unless an alternative venue is preferred. I will discuss the practicalities of being available for an interview lasting up to two hours and whether contingency plans are necessary.
- The referrer will be informed when someone agrees to participate in the study and again when their participation is completed.

Informed consent

- I will make it clear in my initial phone call that the potential participant is under absolutely no obligation to take part in the study and may withdraw at any point without it affecting their support or their partner's care.
- Before commencing the interview I will go through the 'Information for Participants' leaflet and make sure it is understood before asking participants to sign the consent form.

Risk to Participants
I do not envisage that this study will have an adverse effect on those participating. At the same time, I will be inviting the participants to reflect on some potentially difficult topics and it may be that a participant could become upset over the course of the interview. I hope that, as an experienced psychotherapist, I have the sensitivity to conduct the interview in a way to minimise discomfort to the participant. If it should become apparent over the course of my contact with a participant that they require further emotional support, I would discuss with them how this could best be managed and, if necessary, ask their permission to inform the referrer.

Thank you for your help in recruiting participants for this study!

Louise Anthias
Version 2 23/1/12

Appendix VI

Recruitment protocol

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The Last Journey Together: Experiences of Caring for a Partner with Late Stage Cancer at Home.

Protocol for Data Collection in Cooperation with Hospice Staff

1. Hospice staff identifies a potential participant, the partner of a patient in the late stages of breast or prostate cancer currently caring for them at home.
2. Hospice staff member informs the carer about the research, using flyer, and, if the carer is interested, gives them a copy of the 'Information for Participants' document and consent form. If the carer is willing to consider taking part in the study, they may give permission for their contact details to be forwarded to me, by my phone or email above, together with a time convenient for them to be contacted.
3. I make telephone contact with potential participant, give further information about the project and ascertain whether the participant meets the criteria for the project and is willing and able to participate. I will also ask whether their partner is aware of the study and has no objection to their participation
4. If the participant wishes to proceed, I will arrange a mutually agreeable time and place to meet for the interview. I envisage most interviews would take place in the carer's home. Because of the length of the interview, 1.5 – 2 hours, I would discuss how the participant could be available and whether arrangements would be need to be in place for their partner.
5. I will inform the hospice contact that the participant has agreed to take part in the research.
6. I meet with the participant and, if appropriate and desired, briefly with the partner. I will commence the interview by first ensuring the participant has read and understood the information for participants

and, if they agree to go ahead, signed the consent form. I would answer any question or concerns the participant has about the research.

7. I conduct the semi-structured interview based on but not limited by the attached questionnaire. I aware that unforeseen events or the health of the partner may result in an interview being interrupted or terminated. If this was the case I would try to judge if it was appropriate to complete the interview at a later date.
8. At the end of the interview I will run through the 'Guidelines for Keeping a Journal', address any concerns the participant may have about this and discuss alternative methods of keeping a journal if appropriate.
9. I will thank the participant for participating and ensure they are not left in a distressed state before taking my leave.
10. I will contact the participant by telephone after 1 week to encourage keeping the journal.
11. After 3 weeks I will meet with the participant, collect the journal and conduct a short 'debriefing' interview to focus on the impact of the interview and keeping the journal. In the case of an email journal this contact may be by phone.
12. I will inform the hospice contact that my contact with participant has been completed.
13. If it should become apparent to me that a participant requires additional emotional support or has been adversely affected by the process of participating in the research I would discuss with them how this could be addressed, by the participant contacting the hospice services or G.P. and/or by my contacting the hospice contact.
14. I will provide written feedback to the participant after data analysis, should they wish it.

Notes

1. I have specified breast and prostate cancer in my protocol as these are the most common cancers in the UK and represent both men and women. I recognise, however, I may have to be flexible in order to recruit sufficient numbers for my study.
2. The first participant's interview and journal would be considered a 'pilot' and my methodology may be slightly amended based on this. The pilot will be included in my analysis.

Time Frame

I now have ethical approval from the Tavistock, IRAS Research Ethics approval and R&D registration with Westminster PCT. I would like to start as soon as participants can be identified and recruited. I envisage a participant would be involved in the project for 4-6 weeks from initial referral. I would hope to complete data collection within 6-9 months although this depends upon finding enough suitable candidates. The methodology I am using for the interviews requires that data analysis will run concurrently with data collection. I would hope to complete the project within 2-3 years.

Louise Anthias 28/05/12

Appendix VII

Guidelines for writing the journal

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Thank you for agreeing to keep a journal. There is no 'right' or 'wrong' way to write your journal. I would encourage you to write something each day, even if it just one line, to give a representative picture of your life and thoughts at this time. I welcome hearing about anything which is currently concerning you but I am particularly interested in you reflections on the following.

1. How are your day to day experiences affecting you, both positively and negatively?
2. What are your main concerns currently?
3. How would you describe yourself as a person at the moment?
4. How are your relationships with your partner and family going?
5. How do you reflect on the past, both as an individual and a partner?
6. What are your thoughts about the future?

I would like you to keep the journal for three weeks. I will contact you by phone after one week to see how you are getting on and will collect the journal from you after three weeks. If you decide against keeping a journal or decide you would prefer not to share it, I will respect your decision. At the end of the project the journal will be returned to you to keep. If you prefer to use another method of recording your thoughts, for example a computer document, an audio diary or by email, this would also be acceptable.

Thank you again and good luck!

Louise Anthias

Appendix VIII

Letter to inform referrer of participation

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Dear ……

Thank you for referring ……to me for inclusion in the research project concerning the experience of carers.

Either:
I am pleased to inform you that …… has agreed to take part in the project and I will be interviewing him/her on ……

I will inform you when their participation is completed.

Or:
I discussed the project with them and they have decided against taking part.

Yours sincerely

Louise Anthias

Version 1 18/10/11

Appendix IX

Letter to inform hospice staff at the end of contact

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Dear ……

Thank you for referring …… for inclusion in the research project concerning the experience of carers. Their participation in the project is now completed.

I look forward to sharing the outcome of my research with your team in due course.

Yours sincerely

Louise Anthias

Version 1 18/10/11

Appendix X

Example of a blow by blow narrative

Brian

I have omitted my prompts from this account in order to represent the relentless progression of the disease and the impact on the couple's life.

"There were signs of something not being, being wrong, but I don't think the course of action that happened could have happened earlier, because she kept, you know, being taken to the doctors, like, um I don't think it's the doctors fault, he doesn't have experience of that sort of field, and in his opinion, he just thought she'd got a bad kind of tummy, like."

"She was getting diarrhoea one day and the next couple of days she'd have constipation, and this was going on for a number of months. All of a sudden over couple of weeks, her belly just started swelling up, and it just looked like she was nine months pregnant."

Although Brian does not blame the first G.P for not instigating investigations, he describes taking the initiative for getting a second opinion.

"So I strongly said to her, 'We can't keep going along with our doctors decision, we'll have a second opinion.' And we had a second opinion, by another doctor in the same surgery, and he himself felt there was something much more wrong than indigestion, tummy upset or that."

"So she was sent for blood tests and scans and all that, and within 2 weeks she was whipped up to the hospital and had a major ovarian operation. She spent 2 weeks in there, 2 or 3 weeks in hospital, and then she came out, and obviously she was in recovery like."

Following surgery for ovarian cancer Beth had a number of years in remission before a secondary tumour was found. In the following section Brian again describes taking action to initiate investigation.

"She had to go for blood tests again, and some breast scans and she said, 'Look, I got a lump here on me breast', and I said, 'Well, we'll keep an eye on it over couple of days, it might just be a pimple or a cyst coming up you know, and if it gets sore, then we'll whip you up to the doctor's like', and, unfortunately, that's and that…....and um….the results came back that she'd got breast cancer."

"But then in a short space of time we went from category 1 to category 3. So we went to hospital and they removed her breast, with her request obviously….um, that was a very traumatic time for both of us."

In these extracts above, the use of the plural personal pronoun underlines Brian's sense of involvement in the process. The story continues.

"October time, she started bleeding from her back passage, and she'd been to the doctors a number of times and he said she'd got haemorrhoids, and she started to get agitated. He fixed her up with an appointment to go to the hospital to have some bands fitted which starve them of nutrition, they just drop out naturally, you know."

"Anyway, she took the medication, the operation was sorted out, she went in, as a day patient, and they put this camera up her back passage again, and they went past the haemorrhoids and came across an unexplained growth, so they stopped the operation straight away and, after a little while, they came forward and said, we've done this, we've come across some unknown growth"

"So, this was the start of bowel cancer. Um.. she went again, she had a bowel biopsy done, blood samples, CT scans, um, results came back she had bowel cancer, and within a couple of days, 24th, Christmas Eve, an appointment was made to take her in for an operation, she had an operation for bowel cancer."

"We went to see a specialist doctor, doctor says, 'Um, we're undecided at the moment, what course of medication we're going to put you on because we've come across shadows on the liver, but we're uncertain, they could be shadows, they could be cysts but we can't decide what to give her for medication until we've done further tests.' So it was backwards and forwards, blood tests, CT scans, another biopsy, um, on the liver. And over a period of time, they started coming around to saying, 'Those shadows, they seem to be moving' They now classed them as metastases, but, 'We're still unsure, so', they said, 'What we'll have to do is to leave it for a little while', do more blood tests and that, another biopsy, more CT scans and now, it's been classed as secondary liver cancer."

Appendix XI

Example of interview tone

Estelle

Overall tone
Friendly, welcoming but some tension apparent from outset.
Estelle was just back from work and was rushing around putting a cake in the oven to be ready when the children came home. I was aware of how pressured her time was and this may have encouraged me to proceed with the interview more quickly than I otherwise may have done, perhaps allowing less time for reflection and leaving some areas less explored.
In early part of interview, telling the story of Evan's illness, there seemed to be a pressure to give the 'blow by blow' account, and to get each detail correct – perhaps a desire to control a story which had been so out of her control.
The phone rang several times in the course of the interview, her husband calling from the hospice it transpired, and eventually I suggested she answer it, she was rather short with him on the phone and I felt somewhat uncomfortable about being the cause of her not having time for him.
In the first half of the interview she was giving a positive account of the couple's closeness and harmony, I felt a disconnect between the account and the strong feeling I was picking up from her. In the later part of the interview, perhaps as she grew more relaxed with me, Estelle was much more explicit in expressing her anger and to a lesser extent her sadness. I was very aware that she has to find a way of surviving, has to keep going and perhaps this also deterred me from exploring more sensitive areas, such as the loss of her mother.

What is missing?
Some sense of them as a couple, both then and now, more talk of roles than the actual relationship. No information volunteered about the sexual relationship and I did not ask specifically. Although Estelle referred to the loss of her mother, this was not explored in any depth.

What is she getting from the interview?
I think space for herself and a chance to be heard, plus the sense that her experience could help others. Telling her story may also have helped her order and integrate a chaotic series of events.

What identities are being performed in the interview?
The good wife
The good mother
The survivor
The overburdened and sometimes resentful or angry woman
The bereft who fears confronting the loss of her partner

What does the narrative do?

The performance of identities
Bears witness to a very difficult period of Estelle's life
Speaks out for carers as a group
Engages the listener
Attempts to make meaning of Estelle's experience

Follow up

Estelle was difficult to contact by phone; on the occasions I tried it was clearly not the right moment, she was very pressured with the children and visiting her husband in the hospice. I was very conscious of how busy and stressed Estelle was and was reluctant to add to her burden and so decided not to contact her again by phone. However, in response to my letter thanking her and potentially ending contact, she phoned me and was valuing of the interview, saying it had been cathartic and she had been thinking about our talk a lot since we met.
Estelle did not complete a journal, I was not surprised because she clearly has a great deal on her plate at the moment.

The purpose of "interview tone" documents

Constructing these documents was the first stage of the analytical process. I wrote them immediately after transcribing and were based upon the transcription and the field notes made shortly after each interview. They afforded the opportunity to stand back and consider the interview as a whole, including both content and process, the work of the narrative and what was missing. They helped me to consider reflexivity. These documents were the first step towards more detailed analytical processes.

Appendix XII

Example of first person summary

Deidre's Story

I haven't had an easy life but I've always just got on with it, what else can you do? I was born in Ireland, the tenth of eleven children. My father was an alcoholic, he used to beat the crap out of my mother, she spent a lot of time in the psychiatric hospital. But we were a strong family, were always there for each other and still are. I came over to England for a holiday with my sister when I was eighteen, that's when I met Dave, I didn't go back home. He was twelve years older than me and had been married before, had a daughter but had no contact with her.

I adapted and settled down here, a few years later I had the kids, but things weren't great. I always said I wouldn't marry someone like my Dad but you don't choose who you fall for. Dave was a drinker too and I didn't see much of him, he was always off down the pub. Eventually I got so fed up that I took the kids and left him, went back home to Ireland. Dave was devastated and begged me to come back, he promised things would be different, so in the end I agreed, it was the right decision because things did change, he didn't want to lose another family. It was thirteen years ago when he first became ill, it turned out he had cancer of the voice box. They removed this and he had to have a valve put in so that he can speak. I have to clean it out every day and change it every few weeks, I hate doing it because it scares me, that I'll do it wrong, but you just have to get on with it. Then last year he started to get ill again, he lost his balance The GP kept giving him pills and sending him away, in the end Dave insisted there was something wrong and finally the GP said he could have a scan.

After the scan we had to wait two weeks for an appointment and by then he was much worse. They found two brain tumours, one on each side, they kept him in and put him on steroids to shrink the tumours, but then he phoned me and said, 'They're going to operate. That seemed to go OK but when they were going to send him home I didn't think he was well enough. It was all very confusing, so many different doctors and not knowing what was happening. Anyway, they sent him home and that night he collapsed and I had to call an ambulance. I told them to take him back to the ward but they took him to A&E instead, six hours we had to wait! Anyway, eventually they took him back in, said the problem was swelling after the operation, and kept him until it had gone down. Then they told us he had secondaries on his lung, that he was riddled with cancer. They said he had three to six months, twelve if he had the treatment. So he's had the chemo, every three weeks, makes him very nauseous, but I don't think it's really helped. I said they should give him another body scan and he's having that next week. Then they might give him radiotherapy. He's not well in himself, he has no appetite, he's lost so much weight. He does have pain in his chest but the morphine helps.

There have been so many nurses, doctors, OTs, but none of them have helped me much. I don't have any help washing him or anything, I do it all myself, but then, Dave wouldn't want anyone else doing it. He can still get to the toilet and into the chair and bed on his own but that's about all. The Macmillan people gave us some money for a drier and I used it to buy a wheelchair and some new sheets and underwear for him. The wheelchair has been a big help and Macmillan also helped me to get the carer's allowance which has also been a help. Dave does get downhearted sometimes, doesn't say anything but I can see it. Then I feel down too, and if he eats, I eat, I react to him. We don't really talk about things much but he has said he'd like a humanist funeral. I'm a Catholic and Dave is Protestant but he's not religious. It's not been a problem really although I didn't dare tell my Mum and Dad that he wasn't a Catholic. When the kids were young I took them to Ireland and had them christened, I didn't tell Dave and he wasn't very pleased when he found out!

My son and my daughter both live very close but we don't see much of either of them now, they just don't seem to be there for us. It's really hurtful because we used to be close. My daughter was married and has two boys and I used to see a lot of them, helped raise them. Then she broke up with her husband and took up with this girl, I try hard but I find it really hard to accept and worry about the effect on the kids. Now I hardly see them, I really miss them. My son lives on the estate but, since he's been with this girl and they've had their daughter, we don't see him much either, his girlfriend isn't family minded and I haven't even been in their flat. I've told them what I think of them and they say they have their own lives, but my son said. 'I do love you, Mum, but you have to tell me what you want me to do.' So I've asked him to come to the hospital with us next week, we'll see, but I think they are selfish.

My own family have been very supportive even though there have been so many deaths in the family these last few years. My youngest sister is really good, she phones me every night to see how things are and she's been over from Ireland several times. Dave's sister has also been good and his daughter from his first marriage, they're back in touch now and that's great. I've worked most of my life, I work at the school as a dinner lady but I've had to take time off since Dave's been ill because I can't leave him for long and have to take him to all his appointments. I really miss my job, I miss the banter, I still see the girls I work with when I can. I enjoy that but I don't talk about how things are with Dave, what can I say? I don't want to get upset, I want to have a break.

Sometimes I get very scared of what might happen, I can be fine and then it just gets to me. At night I sometimes get up and then I have to go back to bed, just so I can hear him breathe, if I can hear him breathe I'm all right. When I'm out I find myself rushing back because I'm scared of finding him dead. I'm not sure what I will do when he dies, it worries me that I might lose the flat because it's too big. I think I might go back home to Ireland, at least my family are there, that's what Dave thinks I should do because I don't see the kids much anyway. Or I could stay here, get a smaller flat in the same area and get another job.

I sometimes think, ‘I didn’t sign up for this’, I also think, ‘If it were the other way round, would he be looking after me, or would he be down the pub?’ But, I don’t know, you just get on with it, don’t you?

The purpose of the summary

Writing a summary in the voice of the participant was one of the first steps toward analysis. It helped me to both view the narrative as a whole and to closely consider the participant's perspective and concerns. It helped me to crystallise the most important aspects of the narrative. In this example the summary helped me to recognise Deidre's particular narrative style and how she constructs her past and present experiences. Because of the length of a transcription it can be hard to maintain an overall focus when analysing segments of dialogue. the summary, along with other narrative techniques, was critical in helping me to move in and out of the detail of the story during the analytical process.

Appendix XIII

Example of letter written (not sent) to a participant

Letter to Estelle

Dear Estelle,
Thank you for your time and for sharing your story with me. Our conversation has helped me to appreciate several important issues affecting you and your life, many of which may also affect other people in your situation, who are faced with losing their partner.

Firstly it helped me to understand the accumulative impact of the bad news and suffering so often associated with a terminal diagnosis, both for the person with cancer and their partner. In your 'blow by blow' account of the journey from the first symptoms through diagnosis, treatments and relapses right up to today, you illustrated vividly the effect this has had on your family and yourself. It seemed important to you to get the story straight, perhaps in an attempt to impose order on a period of your life which has been so chaotic and out of your control.

Secondly, you helped to remind me that a terminal illness in a partner does not happen in isolation, it occurs against the backdrop of other life events and experiences. In your life this includes losing your mother to cancer only last year. I realise how important your mother was to you and it must have been hard to mourn her loss while caring for Evan who was so ill at the time, and knowing that you would be losing him too.

You have painted a powerful picture of the dilemmas of being a mother at a time like this. You are trying so hard to be a good mother to your beloved children and to help them deal with the current illness and future loss of their father. You are sensitive to their needs as adopted children who have only known the security and stability of the love and home you and Evan have provided for the last few years of their lives; and yet now they must face losing him. You have experienced some anger and resentment towards Evan for leaving you with the two children; you would not have chosen to be a single mother. At the same time you recognise that having the children has helped you to get through this difficult period and bring you hope for the future.

You have helped me to realise that you are not only dealing with the illness and future death of Evan but also with the loss of the man he was; you feel he has changed. The illness, treatments and medication have had an impact on both his appearance and his behaviour and, although you try hard to be understanding, this has led to conflict between you. In talking to you, Estelle, I had the sense that you are just holding on, just keeping afloat, while just under the surface many strong emotions are at play. Although you know that you must lose Evan, you avoid contemplating a life without him, as you say, you just don't want to go there. You have reminded me that accepting the loss of someone so dear to you is never easy, never straightforward, but a path with many twists and turns. Thank you for sharing your journey with me.

Purpose of the letter to a participant

This analytic technique, suggested by Frank (2010) is designed to elucidate what the analyst appreciates and has learned from the narrative. These letters should be personal and are not intended to sent. In this exemplar, writing the letter to Estelle highlighted the relentless nature of the illness narrative and the impact on the couple relationship. It underlined the dilemmas of being a mother while caring for a dying partner. It helpful me recognise the multiple positions on accepting loss, spoken and unspoken narratives and the couple narrative. Writing the letter also helped clarify my relational reflexivity. Estelle was a woman for whom I felt a great deal of sympathy, and the letter helped me consider how this might impact on my analysis.

Appendix XIV

Letter to a narrative

A letter to Colin's narrative

Dear Narrative,

So much thought has gone into you and there seems to be so much you want to achieve. You have drawn me into Colin's world and given me a glimpse of his life; even if it is a snapshot, a moment in time. Your first, and perhaps most important, task has been to tell the story of "*a love affair which has lasted for forty six years*", through thick and thin, health and illness. It seemed important to you that I appreciate the strength of the couple bond and what good times have been enjoyed together.

Your next task has been to show me who Colin is, how he wants to be seen and how he has excelled as a husband, father and member of the community. This was softened by the self- depreciating humour used throughout the interview. You have shown me how well Colin has cared for Carol since she became ill and sought to make each moment special. You have shown me how Colin has brought his past experiences to bear in the present, the story of caring for his mother being embedded within you. In the interview you recruited me into constructing an optimistic account of Colin's life, you were eloquent, you were charming and entertaining, but this was also a time of sadness and loss and this was given little space. Perhaps the context of the interview determined this, with Colin seeking to protect not only himself but Carol from distress.

It was in the journal that you allowed darker reflections freer rein and allowed me to see Colin's fears and vulnerability. You showed me how he fears losing not only his identity as part of a couple but his identity as a man. You dared to glimpse into the future and contemplate Colin's life alone.

Thank you for all you have shared with me. You have taught me the importance of looking beneath the surface, to seek out and appreciate the complexities and nuances of stories such as yours.

The purpose of writing a letter to the narrative

Writing to Colin's narrative helped me to consider the work of the narrative, how Colin used the interview and journal to construct his experiences and couple relationship. In this exemplar it highlighted the contrast between Colin's positive performance of self in the interview and the written self which prompted expression of less privileged narratives.

Appendix XV

A story from the perspective of another character

Deidre's daughter's story

I know Mum's had a difficult time, but she really doesn't make life any easier for herself. She talks a lot about her early life, how poor they were but how they stuck together and supported each other and I'm sure that's true but she doesn't seem to understand that things are different now. I know she's disappointed in me, that I don't come round more, that she doesn't see the kids as much as she used to, that I'm not the daughter she wants me to be, but I'm disappointed in her as well.

When I split up with my husband and started seeing Stacey (my girlfriend) it was a very stressful time for me time for me and I could really have done with some support. I'd known for some time that I might be gay and that the marriage wasn't right for me but it took a lot of courage to face up to it and make the break. Mum always claims that she's not homophobic but she is. Anyone can see she doesn't like Stacey, just puts up with her because she has to, and that's part of the reason why we don't go round more often.

Mum complains that it's not fair on Dad that we don't see him more, but I don't know that he's that bothered, he's so ill now anyway. I know he loves us in his own way and I think he knows that we love him. He doesn't talk to us much, never has done to be honest, just sits in his chair and watches the telly. I think Mum is just trying to make me feel guilty.

It is sad, though. We used to be really close, Mum, my brother and me, we had good times together and when the kids came along she was a real help for the first few years. I know she loves them to bits. I do still love Mum and I miss her, I just feel so helpless and she seems to manage well without me. If she could only let me know what's going on and say what she wants from me, I'd do what I could for her, really I would. But she's got to understand I've got my own life to lead in my own way, and that may not be the same as her way.

The purpose of a summary in the voice of another character

This is a technique suggested by Frank (2010), who reminds us that interpretation requires seeing a story from other positions. In this exemplar, I was struck by Deidre's force of feeling when describing her relationship with her children and thought it would be helpful to explore this from an alternative perspective, that of her daughter. This summary is obviously based on supposition but worked to help me consider multiple positions on the relationship. I considered how different cultural and generational expectations and previous narratives could be informing the Deidre's account of the relationship.

Appendix XVI

Transcription Protocol

The interviews were recorded on a digital recorder and I transcribed them all shortly after the interview, thus ensuring they were still relatively fresh in my mind. I first listened to each interview in it's entirety to remind me of the tone of the interview and give an overall perspective. I then listened very carefully to the interview, some sections several times, and transcribed it verbatim, as accurately as possible. My speech was included in the transcript.

Short pauses were recorded with three dots (...) and longer pauses as [pause].

".... But, um… he's [pause] I said, 'Are you alright?'...."

Fillers and repairs, *(um, er)* and positive utterances, *(mm, yeah, OK)* were all included.

".... Er, David's 66 and I'm 54..."
".... Mm, so when did you sort of realise that?...."

Broken off or interrupted speech were signified with a dash (-)

".... it's like he's - my sisters had went away to my brother's place, cos his wife had lung cancer..."

Omitted text in excerpts is marked [...]

Words heavily emphasised are **in bold type.**

Direct speech within fragments of the participant's speech was recorded with single rather than double quotation marks.

"And my friend at work, she said, 'Something's got to be done', she said"

Expressed emotion, such as tears and laughter, were also recorded on the transcript.
(laughter)

Speech which I was unable to make out after listening several times was recorded as: *(inaudible)*

The paper diaries were copied as accurately as possible before returning the original to the participant and the email diary was downloaded and analysed directly from the text.

Appendix XVII

Email from participant (Colin) after completing a journal

Dear Louise,
Doing this has been an experience, I can't find the right words to describe it. Cathartic is way too strong, therapeutic implies that there is something wrong and beneficial is too mimsy. If anything I think it is like going to the confessional. When we met before we started this I asked you if you thought it might produce something akin to an emotional Hawthorn Effect.

To answer my own question I think that it does. During the course of a day emotions and memories flit through my mind. Normally they are transitory, they pass through and are forgotten but because I'm writing the Journal I have to remember them and put them down in some semblance of order and discard some that insignificant, which means I think about them (can you think about thoughts ?) I anticipate that I will continue keeping a journal for the foreseeable future.

I look forward to hearing from you,
Regards

"The Hawthorne effect is a term referring to the tendency of some people to work harder and perform better when they are participants in an experiment. Individuals may change their behaviour due to the attention they are receiving from researchers rather than because of any manipulation of independent variables." (Cherry, 2008)

In his use of this terminology from Social Science literature, Colin positions himself as a fellow professional commenting on the process of the research. He demonstrates self-reflexivity in noting the effect of keeping a journal on himself. He is prompted to hold onto thoughts and emotions which would otherwise drift away and to take a meta-perspective on them. This is thus likely to promote further reflection and processing in a reciprocal loop.

Appendix XVIII

Letter of favourable opinion from IRAS

NHS
Health Research Authority

NRES Committee London - Camden & Islington
REC Office
Maternity, Level 7
Northwick Park Hospital
Watford Road
Harrow
HA1 3UJ

Telephone: 0191 428 3316
Facsimile:

24 April 2012

Mrs Louise Anthias
16 Belmont
Bath
Avon
BA15DZ

Dear Mrs Anthias

Study title:	**The Last Journey Together: Experiences of Caring for a Partner with Late Stage Cancer at Home**
REC reference:	**12/LO/0448**
Protocol number:	**n/a**

Thank you for your letter of 23 April 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Advertisement	2	23 January 2012
Covering Letter	from Louise Anthias	27 February 2012
GP/Consultant Information Sheets	1	18 October 2011
Investigator CV	for Louise Anthias	27 February 2012
Letter from Sponsor	from Dr Rob Senior, Medical Director	02 February 2012
Other: CV for Academic Supervisor - Dr Charlotte Burck		
Other: CV for Academic Supervisor - Liz Forbat		
Other: CV for Academic Supervisor - Reenee Singh		
Other: Letter to inform referrer re. Carer's participation is completed	1	18 October 2011
Other: Unfavourable opinion letter		01 December 2011
Other: Risk assessment form	1	
Other: Appointment letter to participate before interview	2	23 January 2012
Other: Guidelines for keeping a journal	2	23 January 2012
Other: The research interview	1	18 October 2011
Other: Protocol for data collection	2	23 January 2012
Other: Letter to inform referrer of participation in and completion of participation in project	1	18 October 2011
Other: Letter responding to points raised in provisional opinion letter		23 April 2012
Participant Consent Form	3	17 April 2012
Participant Information Sheet	3	17 April 2012
Protocol	1	27 February 2012
REC application		27 February 2012
Response to Request for Further Information		23 April 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/LO/0448	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

J Brown

pp **Ms Stephanie Ellis**
Chair

Email: jmb123@talktalk.net

Enclosures: "After ethical review – guidance for researchers" SL-AR2

Copy to: *Dr Rob Senior, Tavistock and Portman NHS Trust, 120 Belsize Lane, London, NW3 5BA*

Ms Sylvia Westrup, NW London Research Governance Unit, Room 334, Reynalds Building, St Dunstans Road, London, W6 8RP

Appendix XIX

UEL Ethical approval letter

SCHOOL OF HEALTH, SPORT AND BIOSCIENCE
Dean: Professor Neville Punchard PhD FIBMS FHEA
uel.ac.uk/hsb

School Office
Ms Louise Anthias

16 Belmont
Bath
Avon
BA1 5DZ

19 December 2014

Dear Ms Anthias

University of East London/The Tavistock and Portman NHS Foundation Trust: research ethics

Study Title: ***The Last Journey Together: Experiences of Caring for a Partner with Late Stage Cancer at Home***

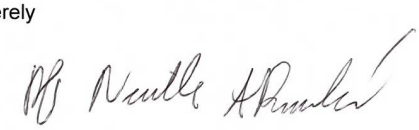
I am writing to inform you that the University Research Ethics Committee (UREC) has received your NHS approval letter, which you submitted to the Chair of UREC, Professor Neville Punchard. Please take this letter as written confirmation that had you applied for ethical clearance from our UREC at the appropriate time it is likely it would have been granted. However, this does not place you in exactly the same position you would have been in had clearance been obtained in advance. Therefore, when responding to any questioning regarding the ethical aspects of your research, you must of course make reference to and explain these developments in an open and transparent way.

For the avoidance of any doubt, or misunderstanding, please note that the content of this letter extends only to those matters relating to the granting of ethical clearance. If there are any other outstanding procedural matters, which need to be attended to, they will be dealt with entirely separately as they fall entirely outside the remit of our University Research Ethics Committee.

Stratford Campus, Water Lane, Stratford, London E15 4LZ
Tel: +44 (0)20 8223 4477 Fax: +44 (0)20 8223 4965
Email: hsb.pa@uel.ac.uk

If you are in any doubt about whether, or not, there are any other outstanding matters you should contact Mr William Bannister at the Tavistock and Portman NHS Foundation Trust (e-mail WBannister@tavi-port.nhs.uk).

Yours sincerely



Professor Neville Punchard

c.c. Mr Malcolm Allen, Dean of Postgraduate Studies, Tavistock and Portman NHS Foundation Trust
Mr Will Bannister, Associate Director, Education and Training, Tavistock and Portman NHS Foundation Trust
Professor John J Joughin, Vice-Chancellor, University of East London
Mr David G Woodhouse, Associate Head of Governance and Legal Services

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